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"Gypsy, Traveller and Roma Health and Social Work Engagement"

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Principal Authors: Professor Margaret Greenfields (Buckinghamshire New University/IDRICS) Sarah Cemlyn (University of Bristol) Jenni Berlin (Buckinghamshire New University, University of Eastern Finland)

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Acronyms

ABCD	Asset Based Community Development
BAAF	British Association for Adoption and Fostering
CCG	Clinical Commissioning Group
CoE	Council of Europe
CRED	Centre for Rights, Equality, and Diversity (Warwick University)
DCLG	Department of Communities and Local Government
DG SANCO	Directorate General for Health and Consumer Affairs
DH	Department of Health
EARNS	European Academic Network on Romani Studies
EC	European Commission
EHRC	Equality and Human Rights Commission
EPHA	European Public Health Alliance
ERRC	European Roma Rights Centre
FFT	Friends, Families and Travellers
FP7	Framework Programme 7 (EU)
FRA	European Union Agency for Fundamental Rights
GP	General Practitioner
GTAA	UK Gypsy Traveller Accommodation Assessments
GTR	Gypsy, Traveller, Roma
GRTPA	Gypsy Roma Traveller History Month
GRTPA	Gypsy, Roma and Traveller Police Association
HWBB	Health and Well-Being Board
IDRICS	Institute for Diversity Research, Inclusivity, Communities and Society
JSNA	Joint Strategic Needs Assessment
LeedsGATE	Leeds Gypsy and Traveller Exchange
LPA	Local Planning Authorities
MFC	Multi-Faith Centre (University of Derby)
MMR	Measles, Mumps and Rubella
MWG	Ministerial Working Group
NFGTLG	National Federation of Gypsy and Traveller Liaison Groups
NGO	Non-Governmental Organization
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- NPPF National Planning Policy Framework
- NRIS National Roma Integration Strategies
- OSF Open Society Foundation
- PPTS Planning Policy for Traveller Sites
- RCC Roma Community Care
- REC Racial Equality Council
- RSG Roma Support Group
- SDOH Social Determinants of Health
- SW Social Worker
- TFR Total Fertility Rate
- TM The Traveller Movement
- WHO World Health Organisation

Executive Summary

The thematic meeting "*Gypsy, Traveller and Roma Health and Social Work Engagement*" held on December 4th 2014 was jointly funded by The European Academic Network on Romani Studies and Buckinghamshire New University and developed and convened by Professor Margaret Greenfields, together with Dr Teresa Staniewicz of Warwick University, Dr David Smith of Greenwich University, and Dr Anthony Donnelly-Drummond of Hull University and key non-governmental and civil society organisations. The seminar was hosted by the Lankelly Chase Foundation, and included twenty four invited delegates from a broad range of medical and social care policy, practice and academic specialisms and was primarily UK focused. It comprised five elements: an introductory scene-setting keynote session on European and UK health policy; two workshops on specific aspects of health care; one on social work; and a plenary discussion.

The core aim of the meeting was to define best practice in policy approaches from a broad academic and practice evidence base as set out by the range of invited experts on Gypsy, Traveller and Roma (GTR) issues and discussed and developed in workshop groups. In meeting this aim the convenors have met the objective of the European Academic Network on Romani Studies to allow for the implementation of better conceived policy initiatives based on reliable evidence.

Health Presentations and Workshops

The relationship between the poor health status of Gypsy, Traveller and Roma (GTR) people and the social exclusion experienced in different EU member states has been widely documented. The social determinants of health (SDOH), including poverty, stress, unemployment, substance misuse, poor quality accommodation, early childhood development, access to a healthy diet and physical activity, profoundly influence individuals' life expectancy, risk of illness or disability and opportunities to lead a physically and psychologically healthy life. They are key to understanding the health status and wellbeing of populations and a matter of social justice. The implementation and monitoring of activities designed to improve the health status of Roma populations is a required strand of National Roma Integration Strategies (NRIS) throughout the EU.

A World Health Organisation (WHO) report on SDOH identified two broad areas which require attention in order to address the improvement of health holistically, namely 'daily living conditions'. These include: physical environments; employment; social benefit protection and access to health care; and equitable distribution of resources, income and power; with particular reference to political empowerment; gender equity and economic inequalities. The WHO report also explicitly identified social exclusion as a key cause of health inequities amongst ethnic minority and migrant communities and this approach has profoundly influenced approaches to improving the health situation of Roma populations, given recognition of multiple exclusions experienced by the communities throughout Europe.

Despite localised good practice, and the success of Roma Health Mediators in several European countries in addressing poor health conditions among Roma, recent European Commission studies report consistent inequity in morbidity and mortality when Roma and non-Roma are compared, most starkly in relation to life expectancy - including maternal, infant and child mortality. All reports reiterate that member states should emphasise the critical importance of taking an SDOH approach to assessing and understanding the health status of Gypsy, Traveller and Roma populations when measuring outcomes. Despite NRIS priorities, *"the main challenge [for] the framework …is in levering transformational change in political will in countries where there is entrenched discrimination and prejudice against Roma populations in public and political spheres"*¹. Indeed solutions for better health and rights come most often from Roma communities themselves.

Introductory Session:

- Professor István Szilard, Chief Scientific Advisor WHO; University of Pécs, Hungary: Policy and Practice Challenges in improving Gypsy, Traveller and Roma Health in Europe
- Dr Ray Earwicker, Health Inequalities Unit, Equity and social Inclusion Branch, Department of Health: **Department of Health responses and approach to improving GRT health in the UK**

Key concerns:

- The critical importance of the Social Determinants of Health approach (underpinned by the 2010 Marmot report) given the profound interrelationship between the poor health status of Gypsy, Traveller and Roma people and the degree of social exclusion experienced in different EU member states.
- Despite a significant body of EU policy guidance and recommendations and UK Department of Health duties to reduce health inequalities and increase health, inequity in morbidity and mortality between Roma and non-Roma populations persist.
- Limited research data especially for Roma and the failure of the Department of Health to adopt systematic monitoring of the health status of Gypsies, Travellers and Roma in the UK.
- The need to take a whole life/ life-course approach since disadvantage becomes exacerbated over time.
- The importance of sustainable funding, and having a clear national policy lead, together with partnership work with communities to enable them to inform policy and practice and promote empowerment e.g. Roma health mediators.

RECOMMENDATION ONE

✓ Ensure that the EC works with member states to recommend best practice in comparable and internationally compatible data monitoring on the health status and SDOH of Roma populations.

¹ <u>http://www.euro.who.int/___data/assets/pdf_file/0004/251878/Review-of-social-determinants-and-the-health-divide-in-the-WHO-European-Region-FINAL-REPORT.pdf?ua=1</u>

- ✓ Guidance should be issued as a matter of priority by the Commission/WHO (and at the UK level by the DH) to ensure that systematic ethnic monitoring occurs in relation to Gypsy, Traveller and Roma health. There is a need to engage closely with communities who may be suspicious of such exercises, precisely as a result of historical or current experiences of discrimination and racism. Such engagement should ensure that information is provided by civil society organisations which stresses the benefits of such ethnic monitoring and that community organisations are actively involved in designing information materials pertaining to the exercise and providing reassurance on international data protection act duties and responsibilities.
- ✓ Urgent requirement in the UK to amend the Department of Health 'Data Dictionary' to ensure that Gypsies, Travellers and Roma people are at all times included in (ethnically disaggregated) ethnic monitoring categories to enable appropriate monitoring of health conditions, pathways and outcomes. It is important too that Roma are included as a discrete category given the lack of knowledge pertaining to the health circumstances of these populations.
- ✓ It is critically important that the UK adopt a robust Gypsy, Traveller and Roma health strategy which is aligned with the spirit and intent of NRIS Framework and which draws upon best practice and up-to-date data and evidence pertaining to the populations. Development of such a strategy would permit the UK Government to access specific EC targeted funding to support Roma health initiatives and demonstrate a joined up approach which foregrounds the SDOH through engaging with elements which impact on GTR health outcomes such as accommodation, poverty, and health literacy. Any such health strategy should specify and audit monitoring requirements and the steps required to ensure that the health needs of the communities are considered (and appropriately met) in health and multi-agency service planning and within the context of service delivery at the local, regional and national level.
- ✓ Reporting on health data pertaining to Roma communities should be undertaken routinely and on an annual basis to the WHO and the EC; and included in NRIS reports and monitoring documents provided at member state level to enable a clearer national and international picture to be gathered on the health status of the communities as well as permitting of top-level review and analysis of interventions and their longitudinal effectiveness.

Workshop One: Maternal and Children's Health

- Ruth Passman (NHS England, Head of Equality and Health Inequalities)
- Zoe Matthews (Strategic Health Manager) and Chris Whitwell (Director) Friends, Families and Travellers (FFT)
- Helen Jones CEO (Leeds Gypsy and Traveller Exchange (LeedsGATE)
- Gabriela Smolinska-Poffley (Roma Support Group: RSG) RSG Deputy Coordinator and Roma Support and Engagement Programme Leader

Zoe Matthews diverged from her prepared topic on key determinants of health, good practice and cultural competence in maternity care, as these topics were already covered, to consider funding, policy implementation and sustainability, given that policy and guidance over decades have not shifted the inequalities.

Key concerns:

- Importance of terminology reflecting underlying attitudes that empower and promote collaboration and co-production rather than patronise e.g. people who are in vulnerable situations rather than 'vulnerable groups', engagement and dialogue rather than 'non-compliance'.
- Good practice examples match provision to need and location, for example in relation to immunisations, but are not scaled up to meet wider health equality duties
- Importance of ensuring GTR communities are included in assessments of services, planning and commissioning
- Reluctance among health care commissioners to include Gypsy, Traveller and Roma populations in Joint Strategic Needs Assessments or to commission targeted services to meet their needs, fuelled by a combination of apathy, discrimination and lack of hard data.
- Lack of focus at central government level combined with dangers of localism. Existing good practice projects under threat of closure through funding difficulties, short-termism and lack of strategic equality focus by policy makers and commissioners, with the loss of institutional knowledge and individual expertise
- Critical importance of working in partnership and using community development and empowerment models, including story-telling and meaningful narratives.
- Need to overcome barriers of language, communication, understanding of service provision and trust to enable access by Roma. Civil society agencies and community mediators can be key enablers.
- Social work interventions with Roma families can be triggered by 'medical neglect' concerns linked to lack of understanding of pre-migration conditions and exacerbated by communication failures.

RECOMMENDATION TWO

✓ At the UK specific level it was agreed that there is a critical and urgent need for top-down leadership in relation to Gypsy, Traveller and Roma health which emphasises enforceable equalities duties in relation to the populations and monitors and enforces the engagement of clinical commissioning groups (CCG) and strategic health and wellbeing boards (HWBB) with the health of the communities. As such there must be accountability at HWBB level to ensure that inclusion health priorities are embedded into their activities.

- ✓ While to some extent the commissioning of services will follow hard evidence of health inequities experienced by the populations (which will arise with ethnic monitoring of health conditions and disproportionate disease burden), it is important that there is a clear and monitored expectation that Joint Strategic Needs Assessments (JSNB) will include the health of Gypsies, Travellers and Roma and will take account of available best evidence on the populations within a locality and the SDOH which impact on them. Commissioning of targeted services should follow guidance such as that issued by Inclusion Health (2013) on best practice in practical steps for commissioning inclusive joint needs assessments and services for Gypsies, Travellers, Roma and other 'inclusion health' priority groups².
- ✓ There is a need at both policy and practice level to explicitly link Inclusion Health priorities into 'person centred care'³, as a tool for reducing multivariate inequalities experienced by the communities.

RECOMMENDATION THREE

Dedicated core funding must be made available for civil society 'grassroots' health projects which are driving Inclusion Health initiatives on the front line. Such projects comprise outstanding levels of expertise coupled with in-depth cultural competence and co-production of activities, health promotion materials and holistic delivery of support which address the SDOH impacting on the communities.

RECOMMENDATION FOUR

- ✓ There is an urgent need to establish a Gypsy, Traveller and Roma Inclusion Health Advisory group with assistance and membership from NHS England; Public Health England, the Faculty of Homeless Health and the Department of Health. Similar Advisory boards should be constituted across devolved Governments (Wales; Scotland and Northern Ireland unless NI prefers to continue working on an 'all-Ireland' basis as is evidenced so successfully in relation to the All-Ireland Traveller Health Report (2010)).
- ✓ The Gypsy, Traveller, Roma Inclusion Health Board must ensure substantial and meaningful representation from across civil society agencies working with the GTR populations and should take account of 'inclusion health' activities undertaken in relation to other vulnerable priority groups (e.g. homeless people, sex workers, vulnerable migrants etc). Funding for travel should be provided to meet the expenses of civil society organisation delegates so as to enable attendance at such meetings. The Health Inclusion Board should also

² See:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/287787/JSNA_and_JH WS_guide_-_FINAL.pdf

³ http://www.institute.nhs.uk/qipp/joined_up_care/patient_centred_care.html

host a virtual platform (with linkages to relevant forums and agencies such as the Roma Health Network; WHO and Council of Europe) to enable discussion, sharing of good practice examples, research examples etc.

- ✓ The Board should work across a number of common strands pertaining to issues of health access, breaches of Equality Act legislation and identifying good practice, policy recommendations etc. It is critically important that account is taken of the changing pattern of health inequalities experienced by the diverse communities and those with whom similarities exist (e.g. increasing vulnerability of 'boater communities' without access to secure moorings) as well as monitoring activities such as patterns of commissioning of services; inclusion of GTR populations in joint needs assessments and representation on HWBBs etc.
- ✓ Good practice guidance and policy on commissioning of services for 'Inclusion Health' priority groups was issued by Royal College of General Practitioners in 2013 (Gill et.al., 2013)⁴.

RECOMMENDATION FIVE

- ✓ In devising interventions and engaging with community members around issues of maternal and child health (including access to ante-natal care; immunisations etc.) there must be a clear commitment to and expectation of co-production and the involvement of community members, peer health mediators, civil society organisations etc. in design of materials (e.g. immunisation leaflets); and activities, to ensure cultural competence and accessibility. An asset-based co-production model must be the default approach in all services targeted at GTR populations.
- ✓ It is critically important to ensure that health professionals receive cultural competence training in engaging with the communities and are alert to the reproduction of stigmatising concepts, language and perceptions in relation to GTR populations. Cultural competence will include knowledge and strategies for engaging with gender-practices, language barriers etc. and awareness of specialist resources which can be utilised to support service users from the above communities.
- ✓ Health promotion activities (e.g. infant nutrition, healthy eating, obesity avoidance etc.) can all be built upon foundations gained in engaging in issues about which there is confidence in community 'buy-in' (e.g. all families want to ensure the health of their children and that women have safe childbirth experiences).
- ✓ There should be an expectation that health promotion activities as well as the delivery of specific interventions or activities should involve community-facing activities (e.g. delivery of workshops in community group settings, innovative practice such as 'street-outreach' on immunisation matters etc.)
- ✓ Activities require investment in existing structure (people; resources; cultural knowledge and taking time to engage with communities). This can be in

⁴ <u>http://www.rcgp.org.uk/news/2013/december/~/media/Files/Policy/A-Z-policy/RCGP-Social-Inclusion-Commissioning-Guide.ashx</u>

conflict with target cultures in the UK but it is necessary that such models are supported as diverting from particular methods of 'doing' and rigid time scales to enable effective processes to be developed and understanding built. For example, there should be scope to enable booking of double or triple length appointments at GP surgeries or ante-natal or child health clinics to enable time to reach understanding about concepts or permit of (appropriately skilled) translation to occur to find a common language (health literacy language as well as a shared 'common tongue') when discussing new or difficult concepts.

Workshop Two: Accommodation Issues and the Impacts on Health and Wellbeing of GTR Communities

- Matthew Brindley (Policy Officer, The Traveller Movement: TM)
- Professor Margaret Greenfields (IDRICS, Buckinghamshire New University)

Key concerns:

- Clear links between inadequate accommodation, on insecure and polluted roadside sites or environmentally degraded public sites and worse health outcomes for Gypsies and Travellers both in terms of access to services and health status.
- Poor access to culturally appropriate accommodation is bound up with experiences of racism and discrimination in the planning system and public discourse, further exacerbating anxiety and reducing health e.g. environmental degradation and negative health impact of some evictions.
- Evidence of Roma being clustered in overcrowded, poor quality housing which impacts on health status, though there is an absence of research on this issue. Critical importance of an SDOH approach being taken when reviewing the health status of Roma households.
- A large percentage of 'housed' Gypsy and Traveller families' transition into conventional housing to avoid repeated evictions from 'roadside' sites or to ensure adequate medical treatment and access to care. Substantial evidence of depression and anxiety amongst housed Gypsies and Travellers, especially women, associated with isolation, loss of community, discrimination and difficulties of transition.
- Also emerging evidence for housed Gypsies and Travellers of increasing rates of drug/alcohol abuse and family breakdown. 'Ticking time-bomb' of the impact on GTR mental health of enforced housing policies and a lack of cultural awareness of their needs.

RECOMMENDATION SIX

✓ With specific reference to the UK context it is critically important that there is top-down guidance to ensure collaborative working between local authorities and Health and Wellbeing Boards (HWBB) so as to collaboratively address the negative impact of accommodation insecurity on Gypsy, Traveller and Roma physical and mental health.

- Accommodation related mental health issues need to be given greater priority in health policy and professional discourse and there is a requirement that psychological wellbeing is emphasised by civil society agencies and health advocates within community discussions. Awareness-raising activities (health literacy) pertaining to the health impacts of insecure or poor quality accommodation should also embed awareness of mental health issues and increase knowledge of culturally accessible resources such as the Traveller Movement DVD on seeking mental health support (aimed at Gypsies and Travellers). Additional relevant resources for health professionals (and service users) include FFT's publications on depression and the report of their wellbeing consultation with clients, and the report from the RSG Mental Health Advocacy project with migrant Roma⁵.
- ✓ In relation to the shortage of site provision for caravan dwelling Gypsies and Travellers and the negative effects of repeated eviction or insecure accommodation, there is a need to urgently review accommodation policy in the light of the equality 'duty to cooperate' and the health equity duties placed on the Secretary of State. Health policy should be embedded into all housing and accommodation policies with the intent of reducing the health outcome gap. There is a need for a system-wide analysis of cause and effect on Gypsy, Traveller and Roma health with careful attention paid to issues of accommodation.
- ✓ There is a critical need for the Department of Communities and Local Government (DCLG) and Department of Health (DH) to collectively and collaboratively engage around health and wellbeing of GTR communities given the overlap of concerns and duties in relation to health, well-being and engaging with SDOH, community cohesion (in the light of widespread public and media hostility to 'unauthorised encampments') and reducing the human and social costs of accommodation related exclusion. Appropriate and effective inter-agency working will also reduce fiscal costs pertaining to health service delivery to Gypsies and Travellers living at unauthorised encampments (see above under maternal and child health) and to local authorities faced with eviction and 'clean-up' expenses.
- ✓ DCLG, the Local Government Association and other relevant bodies including local authorities should promote the use of Negotiated Stopping Places (tolerated stopping places at suitable locations which permit Gypsies and Travellers to access health care and education) based on the model successfully piloted by Leeds Gypsy and Traveller Exchange (LeedsGATE) and Leeds City Council. Use of such options are both low-cost and effective in reducing community tensions and ensuring access to services including much needed health provision⁶.
- ✓ In relation to Gypsies and Travellers resident in housing who do not wish to live in such accommodation, there are both mental and physical health

⁶ <u>http://www.leedsgate.co.uk/2013/11/25/negotiated-stopping-versus-transit-sites-whats-the-difference/</u>

⁵ <u>http://romasupportgroup.org.uk/wp/wp-content/uploads/2011/08/Roma-Mental-Health-Advocacy-Project-Evaluation-Report.pdf</u>

benefits to such residents of supporting self or local authority provision of sites and a freeing up of conventional accommodation for families in need of housing who would not consider or tolerate living in a caravan.

RECOMMENDATION SEVEN

- ✓ Local authorities should take immediate steps to improve the living environment on local authority Traveller sites so they meet the standards set out in the Government guidance on 'Designing Gypsy and Traveller Sites': <u>https://www.gov.uk/government/publications/designing-gypsy-and-travellersites-good-practice-guide</u>
- ✓ Local Planning Authorities (LPAs) should, as routine, engage Clinical Commissioning Groups or Health and Wellbeing Boards when reviewing planning applications for Traveller sites so as to ensure that provision conforms to both Planning Policy for Traveller Sites (PPTS) and the National Planning Policy Framework (NPPF) requirements to promote healthy communities. A NPPF and health and wellbeing checklist is available from the Town and Country Planning Association⁷.

RECOMMENDATION EIGHT

✓ There is an urgent need to commission and undertake research into the housing circumstances and impact of poor quality accommodation on Roma physical and mental health. The impact of such housing issues is relevant not only at individual and public health levels but also (see Workshop Three) has implications for social care interventions in relation to children and families.

Workshop Three: Social Work Engagement with GTR Communities, Good Practice and International Concerns

There is more limited research related to the experiences of Gypsies, Travellers and Roma with social work and specifically child protection interventions, however the substantive studies available reflect themes pervading the health-related literature. These include the complex interplay of material poverty, poor environmental health and housing, accidental injury associated with poor living environments and problems of access to health and education services, thus increasing risks for children and families. This is frequently compounded by troubled relationships between the communities and social care agencies, where pathologisation and racism pervade institutions and affect individual practitioners' understanding and attitudes. For migrant Roma there is the added highly significant dimension of the often unmet need for appropriate linguistic and cultural translation.

Historically social care organisations across Europe have acted on behalf of an assimilatory state in removing Gypsy, Traveller and Roma children from their families to 'educate' them away from their culture. Sadly this trend is reflected in some overly coercive interventions today, underpinned by a lack of professional, informed and dialogic assessments. Mistrust pervades the relationships between the communities and child protection agencies, undermining productive engagement. Where children

⁷ <u>http://www.tcpa.org.uk/data/files/TCPA_FINAL_Reuniting-health-planning.pdf</u>

do enter care, inadequate support is provided in relation to the development of a positive cultural identity because of very limited engagement with communities to promote fostering resources, the cultural dislocation of being placed away from their communities, and, minimal development of cultural resources and dialogue by care and fostering agencies. At the same time there has been a significant increase in child protection interventions in relation to GTR communities in recent years both in the UK and across Europe, although research is limited by the sheer lack of routine ethnic monitoring in most states.

There are however positive practice and guidance developments, although not consistently developed. Some of these were discussed in the workshop, including the community social work model of engagement with families, the guidance now provided by a national fostering agency based on Dr Allen's research, and the support provided by some NGOs to facilitate communication between Roma communities and social care agencies.

- Dr Dan Allen (University of Salford)
- Mr Michael Ridge Lead Community Social Worker from the Haringey Travelling People's Social Work Team
- Dr Viktor Leggio of Manchester University (MigRom Project)
- Dr Phil Henry of the University of Derby Multi-Faith Centre (MFC)

Key concerns:

- In the climate of neo-liberalism, managerialism and budget restricted services, social work services are focused on the situations perceived to be highest risk, with very limited community engagement or family support services.
- GTR families are at risk of being pathologised and disempowered through coercive interventions. Conversely, cultural relativism can impact in not acting when there is a need to do so.
- Failure of communication across different linguistic traditions, cultural expectations in relation to child rearing and in relation to understanding premigration experiences undermine professional assessment.
- Cultural trauma and discrimination experienced by children in out of home settings can be more abusive than the situations from which they are removed. Government policy shifts away from same-culture placements heighten this danger.
- Community Social Work models utilise the concept of partnership working and co-production with the communities to bring about empowerment, collaboration and dialogue through intensive engagement in community forums and inter-agency activities, but these are very rare and in the current climate run against the trends within social care.
- Roma migrants' needs are no different from those of other migrant groups, but they can be conceptualised as more problematic, pathologised and thus inappropriate services, or a 'Roma industry', are developed.

RECOMMENDATION NINE

- ✓ There is a clear need for disaggregated ethnic monitoring across all European member states to establish a clearer picture of the numbers of Gypsy, Traveller and Roma children within the public care system. Such monitoring should take account of the under-lying drivers for entry into care so that it is possible to assess to what extent lack of social inclusion and appropriate models of engagement are implicated in this assumed disproportionality.
- NRIS monitoring reports should include information on the situation of Gypsy, Traveller and Roma children in the care system, as well as measures taken (including a drive to recruit foster carers from such communities) to reduce such care and to enable (where it is safe and possible) children to be returned to their communities and families of origin.

RECOMMENDATION TEN

- ✓ There is a critical need for the adoption of community social work practice (such as is outlined in Michael Ridge's presentation and that of Dr Phil Henry) to enable holistic support and care to be provided to Gypsy, Traveller and Roma community members at risk, as well as enabling communities to share their strengths, develop mutual trust, and participate with services in promoting the wellbeing of children and families and enabling capacity and knowledge-building to occur within agencies and within Roma community settings. Community advocates who can help bridge the gap between services and communities should be embedded into child and family social work engagements.
- ✓ It is critically important that social work training and curricula re-embed concepts of community social work, that social workers in contact with GTR communities are offered access to high-quality co-produced resources and cultural competence training and work in partnership with civil society organisations to provide delivery of the necessary support to the diverse populations.
- ✓ All social work training programmes and professional workplaces should provide sufficient grounding in cultural understanding and sensitivity, developed through a reflexive approach framed by political, sociological and cultural understanding of the context of people's lives. Without such training, families may be pathologised, resulting in unnecessarily coercive intervention, or a failure to provide services when these are required.
- ✓ It is essential to enable professionals to work flexibly where bureaucratic guidelines (e.g. time limits for assessment), simply do not otherwise allow enough time and scope for communicative engagement and sharing of understanding and transparency, or to enable families culturally unfamiliar with British systems to be able to learn about and appreciate the aims of professional social work and support.
- ✓ Where children do need to be safeguarded there is a need to prioritise and enforce the requirement to seek extended family or friends care wherever possible, accompanying this with the provision of support and resources to the alternative carers, including the provision of culturally appropriate accommodation if needed.
- ✓ Work must be undertaken to increase the development of fostering among Gypsy, Traveller and Roma communities so that where children do need to be

safeguarded by entering the care system, there is more possibility of culturally relevant and appropriate alternative care being provided.

✓ Wherever care is provided, there needs to be a sustained focus on enabling GTR children to develop a secure cultural identity. Cultural continuity must become a centralised feature of any care planning process.

RECOMMENDATION ELEVEN

- ✓ Social work and support agencies must ensure that they have access to culturally competent translators and communicators who are able to ensure that 'meaning' is delivered and translated to service users rather than simply words.
- ✓ It is key to ensuring understanding of processes that any materials prepared and delivery of information provided is comprehensible, culturally relevant and understood by recipients.
- ✓ Holistic, wrap around services which offer access to mainstream services (and opportunities for appropriately supported learning opportunities for social care professionals) should be made available to GTR households in contact with social care agencies utilising the community development models outlined by Drs Henry and Leggio and Mr Ridge.
- ✓ To this end there should be sharing of good practice within and across member states and the proposed International Association of Gypsy, Traveller and Roma Social Work practitioners referred to by Dr Allen is to be commended. Such a network can offer both good practice information and support for social work practitioners working with the communities, whilst offering support, guidance and access to peer mentors and role models for Gypsies, Travellers and Roma considering becoming foster carers and/or undertaking a career in social work.



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Introduction and Background to the Thematic Meeting

The thematic meeting entitled "*Gypsy, Traveller and Roma*⁸ *Health and Social Work Engagement*" held on December 4th 2014 was jointly funded by a grant awarded by the The European Academic Network on Romani Studies (EARNS) and additional match-funding generously provided by the Pro Vice-Chancellor's Fund (Society and Health), Buckinghamshire New University. The University of Warwick most generously supported the attendance of an expert delegate from Pavee Point (Katayoun Bahramian), as well as that of Dr Staniewicz, Centre for Rights, Equality and Diversity (CRED) who attended planning and development meetings for the project, co-Chaired the event and provided advice and editing support in relation to production of the final report.

The full funding proposal consisted of an application to support two discrete thematic meetings, the first (held 3rd December 2014) focusing on criminal justice issues⁹ and the second (of which this is a report), on health and social care issues impacting on Gypsy, Traveller and Roma (GTR) communities. Whilst the first meeting (criminal justice issues) had a very broad European dimension, the second meeting (other

⁸ In the UK Gypsies, Travellers and Roma (GTR) is the preferred designation utilised by the communities, and as such recognizes the communities distinct histories of migration to the UK by the order in which named. In European documentation and discussions the preferred term is 'Roma' which encompasses diverse groups including Roma, Gypsies, Travellers, Manouche, Ashkali, Sinti, Boyash and others. Whilst in the main in this report the terms Gypsies, Travellers and Roma are utilised in line with UK practice, on occasion the overarching term 'Roma' is used (typically when referring to European legislation/research or presentations by non-UK colleagues), and where this occurs, the term should be read to include all of the above groups.

⁹ The full report and recommendations from the first thematic meeting (on Criminal Justice issues) will be made available on a dedicated section of the Buckinghamshire New University website from the 20th April 2015 :

http://bucks.ac.uk/research/research_institutes/idrics/Current_Projects/Bridging_the_Gap/ as well as via the websites of participating agencies.

than the key-note 'scene-setting' paper) focused essentially on policy and practice issues pertaining to the UK.

The application for the grant to convene the thematic meeting was developed by Professor Margaret Greenfields, (Director of the Institute for Diversity Research, Inclusivity, Communities and Society: IDRICS) Buckinghamshire New University. Co-applicants were as follows: Dr Teresa Staniewicz, Centre Manager, at the Centre for Rights, Equality, and Diversity (CRED), Warwick University, UK; Dr David Smith, Principal Lecturer in Sociology at Greenwich University, UK and Dr Anthony Donnelly-Drummond formerly of Middlesex University (at the point of application), currently a Lecturer in Criminology at the University of Hull, UK. Agencies and civil society organisations who endorsed the application to the EARNS were: The Traveller Movement London; The Equality and Human Rights Commission; The International Gypsy, Traveller and Roma Police Association and the Association of Chief Police Officers. Professor Greenfields and Dr Staniewicz co-Chaired and moderated both thematic meetings and individual workshop sessions.

The European Academic Network on Romani Studies is a project which runs from 2011-2015. It is jointly funded by the European Union and the Council of Europe. The aim of the European Academic Network on Romani Studies is to support efforts towards the social inclusion of Romani citizens in Europe. The project facilitates intercultural dialogue and raises the visibility of existing research outside the academic community in order to foster cooperation with policymakers and other stakeholders. By creating an interface between academic researchers and political decision makers, while promoting and improving the existing resources on the European Roma communities, the project is designed to ultimately allow for the implementation of better conceived policy initiatives based on reliable evidence.

In September 2013, the Scientific Committee of the European Academic Network on Romani Studies agreed to allocate a proportion of existing Network resources to support actions organised by Network members with the aim of building bridges between the world of academics and that of policy makers. The funding decision was in line with the main purpose of the Network project, which aims to raise the visibility of the existing scientific resources on Roma related issues in order to ultimately assist and improve the planning, implementation and monitoring/evaluation of public policies for the social inclusion of the European Roma population.

It was intended that successful applications to the EARNS to host thematic meetings under the 'Bridging the Gap' funding heading would demonstrate that the subject matter was of core interest to academics and policy makers and that a range of policy makers, practitioners, academics and civil society actors would participate. As a member of the EARNS, Professor Greenfields was eligible to apply for funding to host such a meeting and following discussions with a range of colleagues and agencies in relation to the format of such an event the application was submitted in Spring 2014.

The seminar on Gypsy, Traveller and Roma Health and Social Work Engagement was most generously hosted by the Lankelly Chase Foundation, a leading UK philanthropic charity with a long-standing interest in and commitment to supporting Gypsy, Traveller and Roma projects with the intent of bringing about positive, sustainable, community-driven change. The thematic meeting took place in conference rooms at their Central London offices and we are most grateful to the Foundation for their support, encouragement, generosity and active participation in this event.

The meeting, which in contrast to the previous day's event was heavily UK focused, was accessed by personal invitation only and targeted at health and social care professionals, academics engaged in research on GTR communities' engagement with statutory health and social care services, key civil society agencies and policy specialists from Government ministries. As a result of urgent and relatively unexpected commitments (including emergent public health priorities such that key medical delegates were working internationally on the Ebola crisis, or involved with World Health Organisation activities) a number of potential participants who had hoped to attend were unable to be present.

Overall however the twenty four delegates (the figures include key staff from applicant institutions) consisted of a broad range of policy, practice and academic specialists with medical/health and/or social care expertise. The keynote paper was given by Professor István Szilard MD, PhD, University of Pécs Medical School, Hungary; a Chief Scientific Advisor to the World Health Organisation, specialist in Roma and Migrant Health and convenor of the Roma Health Network for the whole of Europe. Senior Policy leads from the UK Department of Health (Dr Ray Earwicker) and NHS England (Ruth Passman) also presented and participated in workshop sessions, and thus representatives from UK Government agencies were present throughout the entire event.

The meeting operated under Chatham House rules to facilitate open discussion of themes and issues of concern to attendees. The workshop programme and a number of papers and presentations from the event (where permission has been granted by presenters and case details anonymised as required) have been made available IDRICS on the website http://bucks.ac.uk/research/research institutes/idrics/Current Projects/Bridging the <u>Gap/</u> along with images of the events produced by professional photographer Mary Humphrey. Ms Humphrey, who has undertaken considerable work with Gypsy, Traveller Roma populations and in the UK and wider Europe http://www.maryhumphrey.co.uk/, attended the thematic workshop to record proceedings. Her images of the event have been used to illustrate this report of the meeting and policy guidance.

Prior to finalization of the reports of both thematic meetings, delegates have been asked to comment on the document to ensure that they are satisfied that the recommendations and report reflect the discussions and agreed recommendations and to agree sign-off of the document signifying their approval of the content¹⁰.

¹⁰ All content pertaining to individual presentations and the core thematic discussions has been agreed and approved by delegates. Organisations and institutions represented at the meeting were asked if they wished to provide endorsement of the key findings and recommendations of the report through the inclusion of their logo at the end of this publication. In some cases use of a logo may represent contributions to the discussion rather than,

Emergent Themes in the European Context

Policies pertaining to Roma inclusion (for example The OSCE Action Plan on improving the situation of Roma and Sinti (2003) <u>http://www.osce.org/odihr/17554;</u> Council of Europe Recommendation 2006/10 on access to health for Roma and Traveller communities

https://wcd.coe.int/ViewDoc.jsp?id=1019695&BackColorInternet=9999CC&BackColo rIntranet=FFBB55&BackColorLogged=FFAC75; Communication COM(2010)133 on the social and economic integration of the Roma in Europe http://eurlex.europa.eu/legal-content/en/ALL/?uri=CELEX:52010DC0133; Decade of Roma Inclusion (2005-2015) publications; http://www.romadecade.org/news/roma-womenhealth-and-security/9785; the Communication on the Framework for National Roma Integration Strategies up to 2020 COM/2011/0173 http://eur-lex.europa.eu/legalcontent/en/ALL/?uri=CELEX:52011DC0173 and subsequent annual review reports) have consistently highlighted the health inequities experienced by Roma communities across all member states. Indeed the implementation and monitoring of activities designed to improve the health status of Roma populations is a required strand of National Roma Integration Strategies (NRIS) throughout the EU, although the precise format of such interventions and initiatives is determined on a state by state basis (for examples of activities emerging from the NRIS duties see further the the European Public Health report by Alliance. 2014) http://www.epha.org/IMG/pdf/_EPHA_analysis_Health_in_the_2014_National_Roma Integration Strategies -final.pdf

In it incontrovertible that there is a profound interrelationship between the poor health status of Gypsy, Traveller and Roma people and the degree of social exclusion experienced in different member states. It has long been recognised that significant differences exist in health outcomes, morbidity, and mortality rates dependent upon the social positioning and circumstances of individuals and groups (see Wilkinson & Marmot, 2003

http://www.euro.who.int/ data/assets/pdf_file/0005/98438/e81384.pdf). Accordingly there is a key role for public policy at national and EU wide level in shaping and influencing the social environment in a manner which is conducive to improving the health of marginalised populations. The social determinants of health (SDOH) are the conditions in which people are born, grow up, live, work and age and these conditions profoundly influence individuals' life expectancy, risk of illness or disability and opportunities to lead a physically and psychologically healthy life. SDOH are thus a matter of social justice, as health inequity results from the uneven distribution of social determinants which impact on well-being. Thus social gradients (life expectancy which decreases the further down the socio-economic scale an individual is located), stress, unemployment, poverty, substance misuse, poor quality accommodation, early childhood development, access to a healthy diet, physical activity etc. are all key to understanding health status and wellbeing of populations.

necessarily, full agreement with precise phrasing or endorsement of *every* aspect of the recommendations presented within this report.

In 2008 the World Health Organisation (WHO) Commission on SDOH published a Generation" ground-breaking report "Closing the gap in а http://whqlibdoc.who.int/publications/2008/9789241563703_eng.pdf?ua=1 which identified two broad areas which required addressing to improve general health (considered in a holistic manner as including disease prevention, health promotion and the absence of disease). The first realm of SDOH identified within the report consisted of 'daily living conditions' including physical environments, employment, social benefit protection and access to health care. The second focused on equitable distribution of resources, income and power; with particular reference to political empowerment, gender equity and economic inequalities. That report explicitly identified social exclusion as a key cause of health inequities amongst ethnic minority and migrant communities and it is this approach which has profoundly influenced approaches to improving the health situation of Roma populations in the light of the recognition of multiple exclusions experienced by the communities in all member states.

In recent years there has been a significant body of EU policy guidance and recommendations and numerous publications emanating from diverse statutory and civil society organisations which overtly consider broader domains of exclusion as pertinent to NRIS (housing, employment; education and discrimination) priorities when reviewing the health status of Gypsy, Traveller and Roma people.

Such reports vary from those which provide an EU-wide overview of data to countryspecific research such as the European Roma Rights Centre's 2013 publication on the 'Hidden Health Crisis' in Romania which demonstrated profound health inequalities between Roma and non-Roma i.e. a mortality rate for people over the age of 10 which was over three times higher in the Roma population and the average time between first diagnosis of a condition and death being 3.9 years for Roma as opposed 6.8 vears in the general population to (http://www.errc.org/cms/upload/file/hidden-health-crisis-31-october-2013.pdf).

The Fundamental Rights Agency (FRA) survey of Roma undertaken in 2011 <u>http://fra.europa.eu/en/publication/2012/situation-roma-11-eu-member-states-survey-results-glance-0</u> demonstrated that in a number of countries surveyed Roma populations who did not have access to health insurance were substantially over-represented when compared to non-Roma citizens and that health-related limitations on daily activities were more likely to be reported by Roma than non-Roma. Thus for example, in Italy, seven times more Roma than non-Roma report limitations in daily activities due to health and there were similar differences in health status between Roma and non-Roma in the Czech Republic.

Re-analysis of the survey data by gender provided greater evidence of gendered disproportionality in morbidity rates (FRA, 2013 <u>http://fra.europa.eu/sites/default/files/ep-request-roma-women.pdf</u>) such that (p15) "overall, Roma women aged 16 years and over, reported more frequently a 'bad' or 'very bad' health status compared with non-Roma women". In women over the age of 50 self-reporting of such 'bad' or 'very bad' health status was double that of their non-Roma contemporaries with 61% of Roma women aged more than 50 stating that their health status impacted on their ability to undertake daily activities. A FRA report

into multiple discrimination in access to health care (2013 <u>http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf</u>) noted at p93 that "*there is evidence that a large number of Czech doctors refuse to treat Roma*" (perhaps accounting for the variance in limiting conditions reported above in the earlier FRA study) and indeed abundant evidence exists that the problem of discrimination in access to medical treatment is widespread throughout many member states (see below).

One highly successful mechanism (as reported by EPHA 2014. op. cit. and WHO 2014) for enhancing Roma access to medical care has been investment in 'Roma Health Mediators': trained members of the Roma community who act as information sources and advocates for community members in relation to health services. Evaluation of the Open Society Foundation's significant investment in such initiatives reported extremely favourably on the impacts of such initiatives. The OSF report 'Roma Health Mediators: Successes and Challenges' (2011) reviewed mediation programmes in six countries: Bulgaria, Macedonia, Romania, Serbia, Slovakia, and Ukraine. http://www.opensocietyfoundations.org/sites/default/files/roma-healthmediators-20111022.pdf In all countries mediators have "made great strides in addressing the poor health conditions found in Roma settlements in these countries. They have helped increase vaccination rates among Roma, helped clients obtain identification and insurance documents, provided health education to Roma children and adults, and improved health care provider knowledge and attitudes about Roma."

Despite the success of such programmes, the 2009 European Commission funded analysis of the health of Roma in seven member states http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf and the most EU wide health review (European Commission, recent 2014) http://ec.europa.eu/health/social_determinants/docs/2014_roma_health_report_en.p df which analysed the health status of Roma in 31 member states report consistent inequity in morbidity and mortality when Roma and non-Roma are compared, most starkly in relation to life expectancy. The 2014 EC report notes at pp31-32 "a body of evidence demonstrates, among other things, that the Roma population has considerably shorter life expectancy compared to the non-Roma population and face a range of barriers in accessing health". A review of data from a number of member states leads to the conclusion that the gap in life expectancy is between 5-20 years for Roma across the EU. Noting the substantial limitations in comprehensiveness and quality (as well as small sample size) of much EU wide and member state research the report found that assessing the precise links between Roma ethnicity and health is difficult, noting an "urgent need for more research that can further explore the link between Roma health issues and social determinants and reverse current trends".

Accordingly there is a reiteration throughout all reports that member states should emphasise the critical importance of taking a social determinants of health (SDOH) approach to assessing and understanding the health status of Gypsy, Traveller and Roma populations when measuring outcomes. Thus the 2014 EC report analysed the health status of Roma using the following seven indicators: mortality and life expectancy; prevalence of major infectious diseases; healthy life styles and related behaviours; access to and use of health services and prevention programmes; prevalence of major chronic diseases; health factors related to the role of women in the Roma community (e.g. reproductive and sexual health); environmental and other socio-economic factors.

Chapter Five of the 2014 WHO *Review of social determinants and the health divide in the WHO European Region. Final report*

Chapter Five of the 2014 WHO *Review of social determinants and the health divide in the WHO European Region. Final Report here* <u>http://www.euro.who.int/ data/assets/pdf_file/0004/251878/Review-of-social-</u> <u>determinants-and-the-health-divide-in-the-WHO-European-Region-FINAL-</u>

<u>REPORT.pdf?ua=1</u> provides case studies of Roma communities in relation to a number of Social Determinants of Health. Particular attention is paid to Roma inclusion/health within section 5.4.3 of the report (pp103-106), with the authors noting that whilst the NRIS offers considerable scope to improve the wellbeing and health of the population "the main challenge the framework is likely to face is in levering transformational change in political will in countries where there is entrenched discrimination and prejudice against Roma populations in public and political spheres" (p105).

In Buissonniere and Cohen's (2015) short review (published in Eurohealth Spring 2015) of data pertaining of Roma health, they stress that despite NRIS priorities with limited monitoring, variable recording of ethnicity and no clear process for ensuring policy is enacted at the grass roots level, particularly where there is little political will or fiscal support for implementation, *"it is more often Roma communities themselves that are devising and leading solutions that can and have led to better health and rights outcomes for Roma and beyond*" (p9) citing examples of civil society organisations undertaking health outreach, recording of health status of Roma citizens and engagement with legal or international agencies to support individuals challenging health providers or state agencies who are remiss in undertaking their duties. An emphasis is placed strongly on the requirement to ensure that communities are central to the design and implementation of health initiatives with a particular emphasis on the value and success of health mediators in bringing about behaviour change.

Over and above localised examples of health improvements, all of the above reports and publications express continued concern at the deep-rooted and persistent health inequalities experienced by Roma people throughout Europe. As such whilst there is clear evidence (and acknowledgement) of good practice and slow (albeit variable) improvements occurring as a result of the emphasis on health outcomes within NRIS, it is clear that there is a significant need for further research, on-going monitoring and high-level emphasis on enhancing the health status of Roma in Europe.



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Introductory Session/Keynote Papers

Introduction

This opening session, which was designed to 'set the scene' on health inequities experienced by Gypsy, Traveller and Roma (GTR) people in the European and UK contexts, focused on top-level priorities and responses to the disparities in life expectancy and greatly increased morbidity rates within the populations. As such, Professor Szilard's paper reported on broad European dimensions and research which has driven a focus on health within NRIS priorities (see above for a discussion on relevant literature and policies).Dr Earwicker presented on the UK Department of Health response and engagement with duties to reduce disparities and increase health amongst the populations in the national setting. The opening keynote papers thus framed and contextualised the presentations which followed in the following two thematic workshops. Subsequent papers in the 'health-focused' sections of this thematic meeting (Workshop sessions one and two) considered both practice-based challenges to meeting targets and delivering services and front-line initiatives aimed at improving the health and wellbeing of GTR peoples in the UK.

In the context of the UK, despite the lack of systematic monitoring of the health status of Gypsies and Travellers it has been recognised for some considerable time that health outcomes for these populations are significantly worse than those experienced by other ethnic groups. The impact of poor quality and insecure accommodation and disrupted medical treatment for nomadic Gypsies and Travellers have consistently been reported to be a cause of concern (see Matthew, 2008; Cemlyn et. al. 2009; The Traveller Movement, 2012 for comprehensive reviews of health research and SDOH impacting on the populations' health and

wellbeing including data on child and maternal mortality etc.). In 2004 Parry et. al. carried out a study on behalf of the Department of Health which found when compared with age-sex matched comparators, including those from other minority ethnic groups, the health outcomes for Gypsies and Travellers were significantly worse, with reduced life expectancy, increased rates of morbidity and significant increased rates of depression, cardio-vascular disease, diabetes, disability and respiratory conditions.

Extrapolating from Irish data which has found reduced life expectancy in Irish Traveller populations, it has been suggested that in the UK, life expectancy is between 10 and 12 years less for Gypsies and Travellers than other populations (Parry et. al., 2004) although one locality-specific study (Baker/Leeds REC, 2005) reported that average life-expectancy was nearer 50 years of age (approximately 28 years lower than the national average).

Gypsy Traveller Accommodation Assessments (GTAAs – see Cemlyn et al, 2009 for a discussion on the legislative basis of these studies and methodologies/content) which were required to follow Government guidance on data collection pertaining to the needs of Gypsies and Travellers, have, in addition to accommodation data, gathered varying levels of health information pertaining to the populations surveyed. However, methods, quality and level of detail vary from local authority area to area.

Following a focus on the health of Gypsies and Travellers as a priority area (emerging from a policy review of the situation of Gypsies and Travellers under the Labour administration of the early 2000s), the communities have been recognised as a group whose health and wellbeing is of significant interest to the Department of Health. The implementation of the Equality Act 2010 has impacted further by placing duties on public authorities to take action to eradicate discrimination and proactively promote equality of opportunity across relevant protected characteristics. Race is one such characteristic and Gypsies, Travellers and Roma are therefore included within the duties imposed by the Act.

There have been a relatively large number of small scale or local area based surveys of Gypsy and Traveller health needs (i.e. Twistleton and Huntingdon, 2009 http://www.cumbria.nhs.uk/YourHealth/PublicHealthInformation/HealthNeedsAssess mentCumbriaGvpsyTravellersReport.pdf Greenfields with Lowe, 2013: http://bucks.ac.uk/content/documents/Research/INSTAL/703398/B_NES_Health_Stu dy_Report_FINAL_%28Full_report_Inc_Appendices%29.pdf Thompson/LeedsGATE, 2013 http://www.leedsgate.co.uk/wpcontent/uploads/2013/06/Leeds-Gypsy-and-Traveller-HNA-June-2013.pdf) all of which have added to the weight of the evidence in relation to increased morbidity and mortality for Gypsy and Traveller communities.

Migrant Roma have been overwhelmingly excluded from health needs assessments and are surprisingly under-researched in the UK context although the Roma Support Group and several other civil society agencies working with the populations have worked with local health authorities http://www.nelft.nhs.uk/ documentbank/Health care needs assessment Eastern E uropeans_2010_final.pdf to co-produce small scale research studies into Roma health needs, based often on findings arising from front-line intervention work carried out with the communities http://romasupportgroup.org.uk/?page_id=58. Overall, there is very limited evidence to date in the UK on the health status of migrant Roma but what there is suggests health needs and inequities exist which are as stark as those experienced by Gypsy and Traveller populations. Repeated anecdotal and 'case work' evidence from civil society organisations suggests exceptionally high levels of over-crowding in housing and residence in poor quality accommodation with resultant health impacts (e.g respiratory conditions etc.). Roma migrants are also believed to disproportionately suffer from pre-existing untreated health conditions and disabilities arising from pre-migration circumstances (Craig, 2011), which (ongoing research, Buckinghamshire New University, University of Derby and Manchester University with the Roma Support Group and Derby Roma Community Care) appear to be implicated in some child protection interventions when newly arrived migrants seek medical services for children whose health status is sufficient to trigger enquiries and social work engagement. In such circumstances emergent findings suggest that concerns over wilful 'medical neglect' of children appear to trigger referrals to social work teams as health and social care professionals in the UK are unaware or do not take account of pre-migration circumstances which have impacted on access to medical care pre arrival in the UK (see further Workshop Three discussions).

Whilst the evidence on Roma health is sparse, specialist evidence pertaining to the health of Irish Travellers is also limited although in some localities (e.g Leeds) many of those surveyed under the broad heading of 'Gypsy/Traveller' will be of Irish Traveller ethnicity. Given the broad similarities in circumstances (particularly nomadism for a percentage of the population) and relatively large number of Irish Travellers resident in the UK, it is assumed with some degree of confidence (and borne out by small scale studies in mainland Britain) that the health status of Gypsies and Travellers in the UK and that of Irish Travellers in both North and Southern Ireland bear strong similarities. The All Irish Traveller Health Study (2010) http://www.dhsspsni.gov.uk/technicalrep1.pdf is the 'gold standard' of health research pertaining to Gypsy, Traveller and Roma populations in Western Europe, but there is no comparable data set or comprehensive study available for mainland UK.

Despite the fact that the health of Gypsies and Travellers has been recognised as a priority area by successive Governments since the publication of Parry et al (2004), there is a lack of national data on the health status of Gypsy, Traveller and Roma people in the UK. However, in 2011 for the first time the National Census included self-identification categories for Romani Gypsy and Traveller (although not Roma) and the Census found significant over-representation of people within those ethnic categories amongst individuals enumerating experiences of poor or very poor health and/or providing 'care' for another person. For further discussion on the available data see the Office of National Statistics Release of 2014 http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/what-does-the-2011census-tell-us-about-the-characteristics-of-gypsy-or-irish-travellers-in-england-andwales-/index.html and The Traveller Movement, 2013 <u>http://irishtraveller.org.uk/wp-content/uploads/2013/08/Gypsy-and-Traveller-population-in-England-policy-</u>

report.pdf review and critique of the census findings which reveal a significant under-count compared with GTAA data. Despite the availability of national ethnicity codes as utilised in the Census, the Department of Health has failed to adopt similar categories to permit ethnic monitoring of Gypsy and Traveller health service users. There is thus a mismatch in data gathering and available ethnicity categories within and across Government departments as in educational settings (the annual 'school census') children can be identified as being a Gypsy or Traveller of Irish Heritage and it is believed that from late 2015, the option will exist for parents to select 'Roma' as an ethnic category.

However The Department of Health does not currently include the Gypsy and Traveller populations within the 16 + 1 ethnic minority categories currently monitored by the NHS or included within the NHS Data Dictionary and Commissioning Data Set Flows, precluding adequate monitoring of health status and needs of the populations. In any event Roma individuals would, without amendment of the NHS Data Dictionary to explicitly include such an ethnic category, be subsumed under 'White Other' rather than Gypsy or Irish Traveller, such that meaningful data on their health status could not be disaggregated.

In the UK there is no specific NRIS; instead an existing Ministerial Working Group (MWG) on 'preventing and tackling inequalities experienced by Gypsies and Travellers' was tasked with addressing the Roma Integration Strategy Framework for the UK. Although the MWG response was published outside of the deadline for responding to the Framework they drew up a list of 28 'proposed commitments' (many of which drew upon existing activities rather than new or explicit initiatives) which would be adopted. As such health 'commitments' focused predominantly on then on-going work of the Department of Health and the National Inclusion Health Board (which has a focus on a range of vulnerable groups including migrants, refugees and asylum seekers, homeless people and sex workers) to 'identify' needs of Gypsies and Travellers in commissioning health services and to embed training for health care staff on working with vulnerable groups under the Inclusion Health remit. In addition, activities would be undertaken to identify data gaps in relation to core vulnerable groups, identify interventions and seek to reduce maternal and child mortality and increase the uptake of immunisations (see further: 2012 'progress report of the MWG in tacking inequalities experienced by Gypsies and Travellers Section 3: health

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6287/2 124046.pdf)

Surprisingly (and, it has been forcibly argued by civil society agencies, out with the letter and spirit of the Framework) the MWG decided not to engage with or address Roma health (and other) disadvantage. It can be argued that exclusion of migrant Roma from explicit initiatives and targets is not only contrary to Framework expectations but also counter-productive in terms of long-term health planning and cost of treating individuals with conditions which increase morbidity and mortality. Overall, outputs from the Inclusion Health board commissioned research identified

within the MWG documents have been robust and make clear recommendations, but as yet these have led to only limited change.

One key output has been the publication of the study by Inclusion Health/Aspinall (2014) which found "Gypsy, Traveller and Roma communities are amongst the most 'vulnerable' and socially excluded' populations in the UK, noting significant gaps in data impacting on the ability to engage with health improvement. Based on available data however, the report noted that key dimensions of exclusion pertained to the difficulty experienced by these populations in accessing health care, coupled with the need to overcome prejudice and lack of cultural competence by staff.

There have been significant criticisms of the UK Government response to the requirement to develop an integration strategy. Senior legal professionals Willers and Greenhall (2014) in a closely argued review of EU agencies' responses to the UK MWG proposals refer to the series of negative assessments levelled at the UK in relation to inclusion plans for Gypsy, Traveller and Roma populations. In particular they report that in relation to health inclusion "the UK fails to satisfy any of the four basic measures required by the Framework" https://gclaw.wordpress.com/2014/02/06/whats-wrong-with-the-uk-governments-response-to-the-eu-call-for-states-to-adopt-a-framework-on-national-roma-

integration-strategies/. The National Federation of Gypsy and Traveller Liaison Groups (NFGTLG) monitoring report on the UK's progress in integration published in 2014 by the Decade of Roma Inclusion Secretariat (principal authors Ryder and Cemlyn) <u>http://www.romadecade.org/cms/upload/file/9773_file15_uk_civil-society-monitoring-report_en-1.pdf</u>

reported on p27 that EC had given the UK's response 18 out of a possible 22 'negative indicators' commenting critically on the lack of quantifiable targets in the MWG's proposals. See further: <u>http://ec.europa.eu/justice/discrimination/files/roma_country_factsheets_2013/uk_en.pdf</u>

For a fuller discussion on civil society monitoring of the progress of the UK NRIS (health and other domains) see the Traveller Movement (2011) http://www2.ohchr.org/english/bodies/cerd/docs/ngos/ITMB_Gypsy_Traveller_CERD 79.pdf and National Federation of Gypsy and Traveller Liaison Groups (NFGTLG) report. Following a Freedom of Information Act request made by the civil society organisation Friends, Families and Travellers in 2014 evidence has been provided that the last meeting of the MWG took place in 2012 <u>http://www.gypsytraveller.org/picklesgate-government-covers-roma-neglect/</u>. This has been further confirmed by a written response (11/11/2014) by the Parliamentary Under-Secretary of State, Department for Communities and Local Government (Lord Ahmad of Wimbledon)

http://www.publications.parliament.uk/pa/ld201415/ldhansrd/text/141111w0001.htm# 14111164000469 to a Parliamentary Question posed by Lord Avebury, Member of the All Party Parliamentary Group on Gypsy, Traveller and Roma affairs and a leading long-term campaigner on matters pertaining to the well-being and equalities of the communities in the UK.

Seminar Presentations

Professor Szilard (University of Pécs Medical School/Roma Health Network). In his presentation, Professor Szilárd provided a comprehensive review of the

European picture of Roma health; drawing upon WHO data and findings from the 2014 EC survey of Roma health. His presentation focused on both policy and practice challenges to improving the health of Roma people. He stressed the critical importance of health promotion activities with Roma populations as well as structural changes and discussed the 'human resource capacity' approach which the University of Pécs and the Roma Health Network experts favour in their work (i.e. engaging with Roma health mediators to bring about change). Professor Szilard presented and discussed key data from the Council of Europe in relation to the size of Roma populations in varying member states, explaining how poverty, segregation (in a number of member states) and communication barriers (written, and spoken where there is a lack of Romanes translators) have a profound impact on population and individual health. Overall he summarised the headline data in the European context as demonstrating a lower life-expectancy of between 15-20 years; significantly higher levels of infant mortality; high rates of infectious diseases including Hepatitis B and greatly inflated rates of non-infectious 'health-behaviour determined' conditions such as diabetes 2. cardio-vascular conditions etc.

After emphasising the SDOH approach taken by the WHO and EU agencies in overall health strategies for Roma he presented data on both the current 'population pyramid' pertaining to Roma in Europe and the projected population data, emphasising how this varied from other non-Roma populations in member states. Utilising a series of case studies Professor Szilard then illustrated how poverty and the living conditions in Roma camps and settlements in some member states predisposed and exposed residents to conditions such as pyodermia, TB, hepatitis, repeated respiratory tract infections, scabies etc. He stressed the importance of having a multi-agency approach to improving the situation of Roma within and across member states as well as transnational networks of health professionals engaged in this field of research and practice.

One element of Professor Szilard's presentation contained the gross differences in infant and child mortality between Roma and non-Roma in selected member states, as well as differences in birth outcomes (pre-term or normal birth, weight at birth, maternal smoking status etc.) and research into the prevalence of metabolic disease, type 2 diabetes and cardio-vascular disease. He summarised this element of the presentation by noting that there is abundant evidence that in addition to physical health problems there is a lack of health literacy and under-developed awareness of the impact of particular health-related behaviours amongst many Roma in Europe as a result of insufficient or non-existent health promotion activities and low levels of preventative care behaviours and interventions. As such there is a need for collaborative working between health professionals and communities to improve and change health cultures whilst simultaneously tackling broader SDOH such as accommodation, employment, education etc.

Moving on to discuss a recent priority area for the WHO, Professor Szilard linked the Health 2020 priorities of improving the health of Roma and other socially excluded populations to a whole life approach, so that both account is taken of 'health narratives' which are meaningful for populations and collaboration encouraged

between physician and patient. He spoke also of a WHO/University of Pécs led international initiative which focuses on the need to engage with healthy ageing for Roma populations throughout the life-span. A European expert symposium on healthy ageing for Roma in 2014 convened by the University of Pécs and supported by the WHO issued a declaration on good practice in engaging with Roma health and the critical importance of focusing on collaborative practice and community enhancing development in health across the life-span. http://www.euro.who.int/ data/assets/pdf file/0008/262457/Pecs-declaration-final-EDITED_CLEARED_061114_KZ-1.pdf?ua=1. Professor Szilard's paper concluded with the clear message which arose from a series of international workshops on the development of community health assistants. Firstly, that there is a critical need for health promotion for and with Roma people which is core to improving population health. Moving beyond health mediators it is essential that there is a priority commitment to developing Roma community health care assistants who will receive professional training to deliver culturally competent care within their community settings. Such Roma health care assistants will focus on a whole population asset based approach to utilise resources and work with the community in a holistic manner engaging with the SDOH.

Dr Earwicker of the UK Department of Health, lead for the Health Inequalities Unit. stressed that in England the starting point for reducing health inequalities experienced by Gypsy, Traveller and Roma people is to align policy and work to the Marmot approach of Michael whose report of 2010 (http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmotreview) was commissioned by the Government. This report embodies a social determinants of health (SDOH) approach across the life course and underpins activity on health inequalities and public health. See above also under 'European Context' the WHO approaches influenced by the work of Marmot and his colleagues.

The review also recognised that health inequalities grow from social inequalities and that action on these wider influences on health should sit alongside action on improving healthy lifestyles and access to care. The DH believes that there is a critical need to undertake an evidence based approach to health. Given that there is a social gradient to health which cuts across the whole of society albeit impacting particularly on vulnerable groups it is important not to stigmatise particular groups by focusing on their needs to the exclusion of other populations. Accordingly the concept of 'proportionate universalism' (that whilst health care is universally available services should be steered and guided to ensure support is provided to those with the greatest need) is central to the work on reducing health inequalities.

In addition, the DH endorses the importance of taking a life-course approach as it is clear that disadvantage accumulates over time i.e. as is emphasised in the Marmot review and linking to the evidence of premature avoidable mortality amongst Roma populations presented by Professor Szilard in the European health presentation. The DH thus takes as a starting point the need to engage with the link between social structures, SDOH, social gradients and health inequalities. The Marmot Review was commissioned by one Government and accepted and endorsed by a subsequent administration demonstrating a clear commitment to this approach across political lines. In accepting the Marmot analysis, the incoming (2010) Government added a further commitment to "improving the health of the poorest, fastest".

To this end they established a National Inclusion Health Board to establish leadership and probe more deeply into the health status and needs of the most vulnerable groups in society. The work of the Inclusion Health board goes beyond that of Gypsy, Traveller and Roma populations and includes other groups such as homeless people. Reports are (in 2014-15) still being produced as outputs from the work commissioned by the Inclusion Health board. Dr Earwicker noted that the 2014 report on 'Hidden Needs' (Inclusion Health /Aspinall) reported an 'extraordinary catalogue of deprivation and poor health' noting that it is important to address not just life expectancy but healthy life expectancy and guality of life when engaging with health inequalities. He added that he has a particular interest in maternal, infant and child health commenting on the 'horrendous picture' of inequity experienced in both Europe and the UK in terms of differences in low birth weight, limited take up of immunisations, over-representation of Gypsies, Traveller and Roma in measles outbreaks and experiences of childhood deprivation. Overall he noted that whilst the picture is clear, the detail about the precise levels of deprivation is less clear because of the lack of data. Thus he stressed the importance of obtaining hard evidence and data to make the case for best practice and the precise nature of engagement required to impact Gypsy, Traveller and Roma health.

Observing that the UK is internationally recognised for the quality of health data, he acknowledged that there are gaps in data on GTR health and that once such data gathering is improved it will be possible to build a proper agenda to improve health for the populations. He stressed too that whilst there is clear evidence that GTR populations have low health literacy, this is true also of other groups with whom his team work, including 'troubled families' and homeless people. As such there is a need to encourage public health teams to look at the issue of health literacy 'in the round' and engage with all vulnerable groups.

Finally he stressed that it is not enough to simply issue top-down decisions and guidance. It is critically important to work with communities and individuals to achieve empowerment and culturally-competent dialogue to address needs and achieve health improvement for Gypsy, Traveller and Roma populations.

Core discussion points

Given the constituent audience, following a number of questions on EU data sets and how increased mortality and morbidity was analysed across countries, the discussion was heavily dominated by a focus on the UK situation and how this contrasted or reflected broader the European health status of Roma people. It was noted that for UK delegates, other than when large-scale EU wide reports such as those published by the FRA, EC or WHO became available and were widely publicised, it can be difficult to gain knowledge of European initiatives or emergent data pertaining to Roma health. In the UK in the context of increasing levels of Roma migration it is likely that in addition to information pertaining to the UK situation (Department of Health policy, civil society reports, practice guidance etc.) it would be valuable to have a greater knowledge of initiatives being carried out elsewhere in Europe to encourage transnational exchange of concepts around key issues (i.e. healthy ageing for Roma etc.) and policy and practice transfer as well as to raise awareness of the health situation pertaining in countries of origin of Roma migrants.

It was noted that only a few delegates were aware of the Roma Health Network http://www.euro.who.int/en/health-topics/health-determinants/roma-health/romahealth-in-the-european-region of health, policy and civil society specialists (convened by Professor Szilard's team at the University of Pécs medical school and supported by the WHO and OSF) which offers an opportunity for members to exchange news, information on forthcoming meetings and conferences and to upload publications for colleagues to draw upon. In addition Roma Health Network members collaborate closely with the WHO Regional Office for Europe/EC DG SANCO who publish triannual Roma Health newsletters <u>http://www.euro.who.int/en/health-topics/healthdeterminants/roma-health/roma-inclusion-newsletter</u> and disseminate resources which are uploaded onto the recently developed WHO microsite on Roma health issues <u>http://www.euro.who.int/en/health-determinants/romahealth/publications</u>.

One key aspect of the UK system which was noted as having a potentially positive impact on the health of Gypsy, Traveller and Roma citizens when compared to Roma populations in wider Europe, is the availability of universal health care, free at the point of delivery for UK citizens and residents, as well as the availability of free medication (no prescription costs levied) for residents who are on welfare benefits or a low income. Despite this universal coverage however it was reported (see further subsequent presentations) that health outcomes and SDOH in the UK still (based upon such data as we have) demonstrate significant variability in outcomes, morbidity and mortality for Gypsies and Travellers.

Disquiet was reported by a number of delegates (particularly from civil society organisations active in the delivery of front line services) that in the UK there is no clear method of monitoring the health of Gypsies, Travellers and Roma by ethnicity (despite the acknowledgement by the Department of Health (DH) and Inclusion Health of their health vulnerability) as they are not included on the NHS Data Dictionary although many other ethnic minorities are subject to health surveillance (see further. Traveller Movement, 2013 http://irishtraveller.org.uk/wpcontent/uploads/2013/01/ITMB-Health-Report-Inclusion-and-Ethnic-Monitoring-of-Gypsies-and-Travellers-in-the-NHS.pdf). Without this basic level of health monitoring, which it was felt should also be extended to allow for self-identification of Roma migrants, it is impossible to obtain clear base line data on health status and longitudinal change such as may be effected by successful interventions.

Some discussion occurred (and continued following presentations in Session One see below) on the importance of having sustainable funding, as although civil society agencies are well aware of and engage in good practice and partnership working with Gypsy, Traveller and Roma community members, without having a clear policy lead at member state level and an emphasis on the importance of commissioning

services for GTR communities, knowledge is dissipated and services are not delivered to vulnerable populations with commitments remaining at a policy and research level.

RECOMMENDATION ONE

That there is a clear need to ensure that the EC works with member states to recommend best practice in comparable and internationally compatible data monitoring on the health status and SDOH of Roma populations.

To this end guidance should be issued as a matter of priority by the Commission/WHO (and at the UK level by the DH) to ensure that systematic ethnic monitoring occurs in relation to Gypsy, Traveller and Roma health. There is a need to engage closely with communities who may be suspicious of such exercises as a result of historical or current experiences of discrimination and racism. Such engagement should ensure that information is provided by civil society organisations which stresses the benefits of such ethnic monitoring and that community organisations are actively involved in designing information materials pertaining to the exercise and providing reassurance on international data protection act duties and responsibilities.

In the UK there is an urgent requirement to amend the Department of Health 'Data Dictionary' to ensure that Gypsies, Travellers and Roma people are at all times included in ethnic monitoring categories (disaggregated by ethnicity given the varying needs of the three different populations) to enable appropriate monitoring of health conditions, pathways and outcomes. It is important that Roma are included as a discrete category given the lack of knowledge pertaining to the health circumstances of these populations.

It is critically important that the UK adopt a robust Gypsy, Traveller and Roma health strategy which is aligned with the spirit and intent of the NRIS Framework and which draws upon best practice and up-to-date data and evidence pertaining to the populations. Development of such a strategy would permit the UK Government to access specific EC targeted funding to support Roma health initiatives and demonstrate a joined up approach which foregrounds the SDOH through engaging with elements which impact on GTR health outcomes such as accommodation, poverty, and health literacy. Any such health strategy should specify and audit monitoring requirements and the steps required to ensure that the health needs of the communities are considered (and appropriately met) in health and multi-agency service planning and within the context of service delivery at the local, regional and national level.

Reporting on health data pertaining to Roma communities should be undertaken routinely and on an annual basis to the WHO and the EC; and included in NRIS reports and monitoring documents provided at nation state level to enable a clearer national and international picture to be gathered on the health status of the communities as well as permitting of top-level review and analysis of interventions and their longitudinal effectiveness.



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Workshop One: Maternal and Children's Health

Introduction

In the first workshop session (presentations followed by group discussion and feedback and agreement on collective recommendations) the theme was on maternal and child health. Presentations in this workshop session all pertained to the UK situation. As such there was a certain overlap in presentations in reference to existing statistics, research and the state of knowledge in relation to the theme of maternal and child health.

In a change from the anticipated programme (see presentations available on the IDRICS website which includes their prepared paper) speakers from the civil society organisation Friends, Families and Travellers opted to respond to the paper from the DH lead (Dr Earwicker) and discuss the practical challenges of delivering services which impact on Gypsy and Traveller health within the current health commissioning climate in the UK. This in turn generated some considerable discussion during the break-out sessions in relation to sustainability and long-term change in relation to Roma health in the UK (see further below).

Supporting Literature

As noted above, in the UK the overwhelming majority of research pertaining to Gypsy and Traveller maternal or child health has emerged from relatively small-scale

or localised research projects or interventions undertaken by individual medical practices, or developed by local or regional level public health teams. A review of the findings of some of these initiatives (broadly similar in findings in terms of extremely limited cytology screening acceptance, late ante-natal bookings, larger number of pregnancies than found amongst most 'White' communities, low immunisation take-up rate, increased miscarriage rate and limited acceptance of ante-natal screening for disability) can be found in the Cemlyn et. al. 2009 review undertaken for the Equality and Human Rights Commission on "Inequalities experienced by Gypsies and Travellers"

(http://www.equalityhumanrights.com/sites/default/files/documents/research/12inequ alities_experienced_by_gypsy_and_traveller_communities_a_review.pdf Section 3.1:'Health').

Some national level public health data in relation to particular key concerns such as infectious disease outbreaks resulting from lack of herd immunity (particularly measles) and maternal deaths has revealed that Gypsies and Travellers are over-represented in deaths in both of these categories. It has been repeatedly found that Gypsy and Traveller children were more likely than other populations to become ill (or die) in measles outbreaks as a result of non-take up of immunisation (Cohuet et al, 2007). Such information is however relatively 'patchy' and results from analysis of affected populations in response to particular enquiries following preventable deaths/infectious disease outbreaks (see further Traveller Movement, 2012; Matthews, 2008; Cemlyn et, al., 2009; Van Cleemput, 2012).

The 2012 Traveller Movement briefing on health <u>http://irishtraveller.org.uk/wp-content/uploads/2012/03/ITMB-Gypsy-and-Traveller-Health-Briefing-March-</u>

<u>20122.pdf</u> helpfully summarises a number of research studies on maternal and child health and notes (pp 3-4) the key findings from the University of Sheffield/Parry et.al. report (2004) which reported that 29% of their sample of Gypsy and Traveller women had experienced one or more miscarriages compared with 16% of age matched comparators from other ethnic groups and 22% had undergone Caesarean sections compared to 14% of women in the comparator group. Similarly 17.6% of Gypsy and Traveller women reported having experienced the death of a child (of any age and excluding miscarriage) compared with <1% of comparators.

The same publication (TM, 2012) summarises a number of health needs assessments (HNAs) which include data on Gypsies and Travellers, finding within all of these HNAs that health professionals report low uptake of immunisations and a general suspicion of immunisation emerging from the (now discredited) publicity in the UK around concerns over vaccine safety and suggestions that Measles, Mumps and Rubella vaccination (MMR) was linked to increased rates of autism. It is this concern, coupled with the difficulties in achieving herd immunity amongst mobile (nomadic) populations and limited in-reach to communities which has been repeatedly linked to over-representation of Gypsy and Traveller children in measles have occurred outbreaks which in recent vears (DH, 2010 https://www.gov.uk/government/publications/measles-outbreaks-in-gypsy-andtraveller-communities). One report which retrospectively reviewed measles outbreaks in a particular UK region between 2006 and 2009 found that Gypsies and

Travellers experienced a disease burden in relation to such outbreaks which was 100-fold greater than for surrounding communities (Maduma-Butshe & McCarthy, 2012).

Since 2004 Parry al DH the et report for the (http://jech.bmj.com/content/61/3/198.full.pdf) and a localised study undertaken in Leeds by Baker/LeedsREC (2005) which reported an infant mortality rate that was three times higher than in the rest of the 'mainstream' population, there has been no further research (of which we are aware) into infant mortality rates amongst the communities. It is worth noting for comparative purposes that the All Ireland Traveller Health Study (2010) found infant mortality rates amongst Travellers in both North and Southern Ireland were approximately four times that of 'mainstream' populations. Although overall it is reported that there has been a 27% decline in infant mortality in the UK since 2000, overall the member state still has one of the hiahest rates on infant death in Western Europe (http://www.newsmedical.net/news/20140502/New-research-shows-UK-has-highest-infant-mortalityrates-in-Western-Europe.aspx) and in the absence of ethnic monitoring statistics it is difficult to demonstrate any improvement (or whether decline has occurred) in relation to infant mortality rates amongst Gypsy, Traveller and Roma populations.

In particular, there are significant data gaps in relation to Roma maternal and child health in the UK, although the Roma Support Group (RSG - see presentation below) reports that health is often poor amongst their clients as a result of lack of knowledge of health entitlement and how to access the system as well as pre-existing health conditions impacted by pre-migration SDOH, limited English language skills and low educational achievement all of which can be assumed to potentially impact negatively on maternal and child health.

RSG run a Roma health advocacy and information project as do a number of other agencies represented at the thematic meeting, including partners who work with the University of Manchester in the MigRom project and Derby Community Care. In the main there is very limited research evidence on any aspect of health of Roma communities in Britain although persistent anecdotal reports from health workers and civil society agencies who have contact with Roma migrants bear out the comments made by delegates to this thematic meeting (see too Poole and Adamson, 2008).

A limited number of references to Roma may be found in health needs reports on provision of care to East European migrant populations (i.e. the Roma Support Group have worked with health care providers in providing evidence pertaining to migrant communities at risk of viral hepatitis and supported local health needs East assessments targeted at European migrants http://www.nelft.nhs.uk/ documentbank/Health care needs assessment Eastern E uropeans 2010 final.pdf) as well as partnering the East London Foundation Mental Health trust in a psychological well-being project financed by the Pacesetters (DH funded) programme on Gypsy, Traveller and Roma health . An evaluation of all of these projects targeted at the diverse GTR communities in the UK can be found http://www.sheffield.ac.uk/polopoly_fs/1.43553!/file/Final-full-Pacesettershere:

<u>report-edited-with-photos-May-2010.pdf</u>) although there is no specific focus on child health or maternal welfare targeted at Roma migrants.

Occasional localised UK based health assessments which focused on migrant Roma populations emphasise the impact of poor housing on health and relatively high rates of asthma, cardio-vascular disease, Type 2 diabetes and long-term conditions amongst the populations regardless of country of origin (Mahoney, 2006; Moore, 2010) although we were not able to identify specific references to maternal and child health within these limited resources other than references to larger numbers of children than is the norm within surrounding populations. The Salford University report on migrant Roma in the UK (Brown et. al 2013) reported that 38.9% of local authorities who responded to their survey noted that local health services were in contact with migrant Roma and within that report there is intermittent reference to issues in SDOH and accessing healthcare which mirror suggestions by civil society organisations i.e. family size, over-crowded housing, translation issues etc.

Whilst dealing with population total fertility rate rather than specifically with maternal health, a briefing produced by the MigRom project (MigRom Briefing University of Manchester, 2014

http://romani.humanities.manchester.ac.uk/migrom/docs/MigRom_BirthRatesAug201 4.pdf) has found that the total fertility rate (TFR) amongst a group of 44 migrant Roma women from diverse countries and localities of origin is significantly lower than some other research has suggested;, with an average TFR of 2.7 and an average of 29 years. Average age at first birth was 18.5 years. Potentially this may suggest that some changes in child-bearing patterns may be occurring amongst some migrant Roma women with a movement towards later first births and less frequent childbirth although additional evidence is required across other localities and pertaining to differing migrant Roma groups before such conclusions can be drawn. Indeed the MigRom team note particular variations amongst one specific group of migrant Roma from a single location and of a single faith group whose pattern of childbearing is significantly different from the rest of the survey sample (younger age at first childbirth and larger number of children at the point surveyed). Overall it is therefore impossible to generalise at this point in time in relation to child-bearing patterns amongst Roma populations. In their (2014) summary of activities provided through the 'Drop In Service' in Manchester, the MigRom team also report that nine per cent of enquiries to the service pertained to (unspecified) health care support http://romani.humanities.manchester.ac.uk/migrom/docs/MigRom%20briefing%20Oc t%202014.pdf and that they supported a cohort of the 14 Roma (5 male and 9 female) in registering on a food hygiene and safety programme. This latter initiative has potential for improving population health.

Overall however there is a lack of granularity in respect of data for any of the three groups (Gypsy, Traveller and Roma) with the lack of consistent ethnic monitoring creating an insurmountable difficulty in gaining a clear picture of maternal and child health in relation to the populations in the UK. Such data as exists largely emerges from analysis of information in relation to specific public health activities or communicable diseases rather than targeted work with the communities.

Data is held on maternal deaths in the UK (and more recently this has been combined for Ireland and UK offering scope for comparable analysis of Traveller maternal mortality in both member states). In the (formerly published tri-annually) report of the Confidential Enquiries into Maternal Deaths in the UK, 1997–1999 (Lewis and Drife, 2001), found that Gypsies and Travellers have '*possibly the highest maternal death rate among all ethnic groups*', suggesting that this related to late booking, disrupted ante-natal care and that preventable death was more common amongst nomadic women without access to a site or regular medical care. The sixth report covering the years 2000-2002 also noted that Travellers and newly arrived refugees were also at substantially increased risk of death. Subsequent reports referred to vulnerabilities increasing the risk of death (a number of which are found in relation to Gypsy and Traveller populations and which mirror those reported in maternal deaths amongst these groups) but the communities are not explicitly mentioned with a focus where ethnicity is discussed on 'Black' 'African' and non-English speaking migrants.

Thus it is not possible to tell from later reports in the series (the latest Confidential Enquiry report covering the years 2009-2012 was published in December 2014 see summary of findings in the Obstetrician and Gynaecologist online publication (2015; 17: 72-3) http://onlinelibrary.wiley.com/doi/10.1111/tog.12159/epdf) whether Gypsy, Traveller and Roma women are explicitly referred to in such maternal mortality data. Whilst patterns of migration have changed over the past decade and are believed to impact significantly on the demographics of women at risk of maternal mortality (see the confidential reports series above) it is worth highlighting findings from the Save the Children Fund annual review of maternal mortality published in June 104 (State the World's https://www.rcm.org.uk/news-views-andof Mothers Index analysis/news/maternal-mortality-increase-in-uk) which suggests that there has been a 9% increase in maternal mortality in the UK since the millennium, associated with particular high risk and ethnic groups (and with a particularly marked increase in death occurring in London). It is impossible however, given the way in which data has been reported and lack of ethnic monitoring to tell if this increase has impacted in any way on Gypsy, Traveller and Roma populations.

Seminar Presentations

Ruth Passman, Head of Equality and Health Inequalities of NHS England, commenced by explaining both her particular interest in, and personal commitment to, issues of Gypsy, Traveller and Roma health, and her increasing awareness of the range of communities included in such vulnerable populations, such as 'boaters' who experience health inequalities. She noted that her presentation combined data from NHS England activities and 'good practice' examples provided by a GP (PJ Kumar), a medic whose practice in the North of England served Traveller communities and which through culturally competent outreach and co-design of services had increased take-up of immunisation, women's health screening and improved access to maternity care. Dr Kumar had hoped to be present at the thematic meeting but as he was unavailable had provided Ms Passman with data pertaining to his surgery's outreach work to support her presentation.

Ms Passman discussed the widespread prejudice against Gypsies, Travellers and Roma which she encounters in conversations in her personal life and professional settings, stressing that there is a critical need to engage with and challenge stigmatising labelling. She emphasised the belief that there are not 'vulnerable groups' but people who are in vulnerable situations. As such, how terminology is used and what it conveys can be critical to enabling engagement with communities. Accordingly there is also a need for health professionals to rethink concepts such as 'non-compliance' which creates an impression that professionals are the group who know and do 'the right thing' whilst people who challenge their world-view or who are resistant are 'in the wrong'. Such an approach creates barriers instead of the collaborative co-production of health promotion and health literacy discussed in earlier presentations and within group discussions. She highlighted that when engaging with communities around issues of child health and immunisation, it is critical to find common ground as a starting point – for example there can be a key presumption that everyone wishes for health for their children and to be certain that they are acting in a child's best interests.

Ms Passman's presentation on immunisation commenced with a brief summary of key data and reports (see above) pertaining to SDOH which impact on Gypsy Traveller and Roma families then moved on to discuss key initiatives around targets for take-up of immunisation (timing of immunisations, number of immunisations required, etc.). The national childhood immunisation programme is offered routinely through primary care and other health services but there are differences in uptake associated with a range of social, demographic, maternal- and infant-related factors and coverage varies between and within regions. Other than in London, overall uptake of diphtheria, tetanus, pertussis, polio, haemophilus influenza type B, meningitis C and pneumococcal vaccines is above 90%. These immunisations should be completed by the time a child is aged 13 months. Despite this, first doses of MMR (Measles, Mumps and Rubella) vaccinations remain at around 86%. Some groups and individual children are therefore at risk (see above under supporting literature) with Gypsy/Traveller populations regarded as being particularly vulnerable. Where there are rigid expectations over how and when immunisation is delivered it is impossible to meet the needs of travelling communities or those who are highly mobile (which may potentially include Roma who move locations). There is a need to deliver services appropriately and flexibly.

Evidence on health outreach workers delivering immunisation services to GTR communities demonstrates that there is often a mismatch in provision of such services which are not aligned to where sites are located. As such health planning has not occurred and sequencing issues often exist around delivery and take-up of second and third doses of immunisation.

She provided a number of examples of where medical services meet needs of GTR communities (with evidence provided within evaluations of increased take-up of services by both medical staff and GRT populations themselves). Typically these include breaking down barriers to access and engagement, ensuring culturally appropriate service delivery and seeking to ensure that there is a culture match, having records which follow patients etc.

The presentation concluded with Ms Passman summarising NHS England and DH advice on good practice in delivering care to GTR communities. All Primary Care

Trusts (responsible for immunisation services) should contact Gypsy and Traveller communities in their area (both resident and travelling through) and offer outreach immunisations to anyone below the age of 25 years who has not received two doses of the MMR vaccine, or is unsure whether they have. Older unvaccinated adults should also be provided with the service on request. Impromptu in-reach vaccinations should be made available at suitable locations, e.g. GP surgeries, on sites; community gatherings etc. and inter-agency working should occur to encourage the development of contacts who can support such health initiatives (e.g. education, local authority, community contacts, etc.). A particularly good example consisted of a health bus travelling to sites and providing health in-reach, immunisations, health promotion dialogue with community members etc. She concluded by stressing the need to scale up such initiatives and to emphasise to local health care providers and commissioners (health and well-being boards; clinical commissioning groups) their duties to reduce health inequalities and the importance of ensuring that GTR populations are included in 'joint strategic needs assessments' (JSNAs) to enable health commissioning, planning and funding on a more local level. Finally Ms Passman urged that health commissioners and health and wellbeing boards should ensure input from diverse communities at the beginning of any planning phase as she had had conversations with people classified as being from 'vulnerable groups' (including homeless people etc.) who reported that they felt proposals for service delivery targeted at their communities often did not reflect their needs, approaches or lived reality.

Zoe Matthews (Strategic Health Manager) and Chris Whitwell (Director) Friends, Families and Travellers (FFT). FFT is a leading civil society organization working with Gypsy, Traveller and Roma populations nationally. They have a very well established health outreach programme and work with health commissioners. Chris reported that when he was first appointed Director of the organization ten years previously, when cleaning out all documents as they were short of room in the offices, he came across health guidance which cited the need for action and provided similar statistics to that which have been given at the thematic meeting. He stressed that there is a clear need to move beyond policy guidance and research projects which do not bring about change and actively ensure that the health of Roma communities is improved.

Zoe Matthews indicated that although she had prepared a presentation (see the IDRICS website for uploaded resources pertaining to this thematic meeting), the headline data concerning key determinants of health for GTR populations in the UK would be largely similar to that outlined in earlier presentations. As such, and in the light of presentations on good practice in commissioning from senior policy figures (Dr Earwicker and Ms Passman) Zoe felt that there was a need to diverge from the topic on which she had been going to speak (maternal health, good practice in delivering outreach maternity services to Gypsy and Traveller women and partnership working between FFT and community midwives) and discuss the very real problems in transferring policy and guidance into front line service delivery when there was a reluctance for health care commissioners to include Gypsy, Traveller and Roma populations in Joint Strategic Needs Assessments or to commission targeted services to meet their needs.

Ms Matthews indicated that whilst she was able (and had intended) to speak about cultural competence in front line service delivery and development of good practice in commissioning health services for women and children she felt it was critically important to emphasise how policy initiatives which did not transfer to practice, and which were not enforced (for example as a result of no clear measurable commitments by the Government or DH to engaging with and enforcing NRIS health targets) it seemed pointless to discuss initiatives which were short-term and made no substantive change. She provided a brief history of how her significant experience in working as a front line health practitioner (a nurse) and subsequently undertaking research in public health with a community development focus meant that she had both practical and theoretical experience and fully endorsed the comments made by other speakers that it is only possible to bring about change in health status and behaviours by working in partnership with communities and using community development models. To this end FFT sit on numerous Government advisory boards and panels having input into policy. However despite quidance and recommendations there has been a lack of commitment by many health commissioners to making sustainable changes for vulnerable communities.

Emphasising that her team have spent years approaching and seeking to engage with commissioners in relation to health care for Gypsies, Travellers and Roma, Ms Matthews decried (to great acclaim from civil society representatives) the lack of funding which means that even highly successful initiatives and agencies are dogged by short-termism, such that even her own projects and team are likely to be disbanded in 2015 with loss of institutional knowledge and the ability to provide services to communities in need. She reiterated that many civil society organisations feel that a lack of central government leadership and focus means that the many years of experience and knowledge possessed by the participants at the thematic meeting is in danger of being wasted as localism agendas and locality based commissioning means that Gypsy, Traveller and Roma needs are systematically ignored or fail to achieve funding fuelled by a combination of apathy, discrimination and lack of hard data which enables commissioners to deny the need for such services. She noted that a number of good practice examples cited in Ms Passman's presentation while indeed delivering excellent outcomes, have either been closed or are on the verge of closure as DH funding for 'Pacesetters' programmes and the Inclusion Health initiatives draw to a close. In conclusion she applauded initiatives which had been set up but urged that 'those in power' be aware of the lack of impetus at many local levels and called for Central Government agencies to "ensure that people are able to make use of guidance and that there is enforced use of policies and reports which will bring about real change for Gypsy, Traveller and Roma people, as otherwise all the great work carried out for 20 years will come to a standstill and inequalities will increase".

Helen Jones, CEO of Leeds Gypsy and Traveller Exchange (LeedsGATE), supported the statement made by the previous speaker and noted that her organization has been working jointly with FFT on a three year project on improving Gypsy and Traveller health (<u>http://www.leedsgate.co.uk/2015/04/08/health-on-the-margins-reports-and-information/</u>). The project had been funded by the Department of Health. Although project activities are still ongoing and have not completely finished, the funding has now ended and there is still no way of forcing clinical commissioning groups (CCGs) to spend money on improving the health of the

poorest fastest. She then stressed the need for supporting community empowerment models in delivering health care, emphasizing the 'power of storytelling' so that individuals and communities can tell meaningful narratives which have impact and meaning to their people. Otherwise there is a danger of becoming too theoretical and analytical in developing approaches which don't connect with people's lives.

Discussing her experiences and that of the former Chair of her organization (Eileen Lowther) in attending (as representatives of the National Federation of Gypsy and Traveller Liaison Groups (NFGTLG) sessions on Gypsy, Traveller and Roma health at the European Centre for Disease Prevention and Control (ECDC) conference *"Inform, protect, immunise; engaging underserved populations"* in Dublin in 2012, Ms Jones explained how immunization issues had never before been considered by her or her team as being particularly important.

Not only Ms Jones but also many other staff members 'had measles' when they were children, but it was regarded as a common part of childhood in the 1960s and 1970s. She stressed that her experience of the childhood disease while unpleasant had not had a significant impact on her perception of the danger of the condition, but that may have been because she was lucky or relatively well nourished when she contracted it. It was only by attending the health conference, and realizing how dangerous the condition is, and that Gypsies, Travellers and Roma are particularly at risk of contracting measles and other infectious diseases which can cause disability and death, that Ms Jones and Ms Lowther (then Chair of LeedsGATE) realized that it was critically important to begin to develop community resources and engage with immunization issues.

Ms Jones spoke about the impact of the MMR scandal on reducing the willingness of Gypsy and Traveller populations to have their children immunised and related how terms such as 'herd immunisation' and patronizing referrals to 'non-compliance' (as discussed by Ms Passman) could act as a deterrent to engaging with health prevention behaviours. Lack of accessible (in terms of cultural appropriateness and delivery i.e. written materials etc.) information on the importance of immunization and the potential dangers of not having children immunized were barriers to bringing about health behavior change.

She emphasized too that there is a need for bridging models so that community health mediators are in greater contact with health professionals and vice versa and that cultures, languages and knowledge were mutually respected and shared rather than remaining in ghettos – whether that was community health advisors only working with Gypsies and Travellers, or medical and nursing personnel only engaging in clinical settings without mutually sharing knowledge and collaborating respectfully. Essentially therefore to influence change and engage with commissioners there is a need for both top down requirements for duties to be enforced and services commissioned and a 'striking of the balance' which respects the views and priorities of community members, professional health experts and Commissioners. There needs to be a link created between Commissioners, Clinicians, Communities and the Policy community to bring about collective action to enhance health of the communities. Finding a way of working collectively is the most effective way of bringing about change.

Ms Jones also spoke about the under-resourced and under-recognised problem of Alzheimers within the Gypsy, Traveller communities in the UK which is increasingly common and for which no resources exist.

Returning to a focus on immunisation, Ms Jones spoke about her civil society organisation's desire to support knowledge on immunisations and measles in particular. They reviewed information on immunisation which had been designed by Dr Kitching from Public Health England who is a Trustee of the Traveller Movement, and who had worked in partnership with Irish Traveller community members to develop the (2 side) content of the information sheet.

LeedsGATE felt that all the information included in the leaflet was important but that it was a bit 'wordy' for some of their community members and hence potentially inaccessible. Accordingly, working with a designer and team members they set out to design a short, accessible and hard-hitting information piece on measles for use in LeedsGATE's health outreach activities which used far less words and more images. The materials were based on experience and seeking to ensure that they produced hard-hitting information which also didn't buy into the over-arching narrative of Travellers 'infecting' the wider population. Wording was simple and stressed the need to access medical help rather than attending community events if children were unwell or 'spotty'. Options included going to the GP or hospital but the 'right' answer was to call the emergency medical advice line and keep children at home. Leaflets were distributed in community settings such as 'horse fairs' and it was designed by Travellers for Travellers and was very well received. A summary of the project activities and outcomes is available here: http://www.leedsgate.co.uk/information/case-studies/case-studies-immunisationspartnership-work/

A further element of the presentation consisted of a discussion on the importance of developing 'health pathways' which enabled narratives of 'real life' health experiences of Gypsies and Travellers to be assessed, depending upon different potential 'routes' which could occur which could either lead to improved health or ongoing health difficulties which in some cases could lead to premature morbidity or mortality. A cost-benefit analysis was undertaken of certain of these health pathways, which were then used to demonstrate to Clinical Commissioners the fiscal savings of delivering tailored services to Gypsy, Traveller communities in a timely The pathways were jointly developed by Ms Jones and Professor manner. Greenfields drawing upon over 50 years of experience (between them) of working with Gypsy and Traveller communities. The narratives were then fed back to community members for comment and validation before being finalised. They were designed to support a Department of Health funded 'good practice' intervention project, but ultimately there were only financial resources to fund cost-benefit analyses of two out of four pathways pertaining to typical health scenarios. (See LeedsGATE, 2013: http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf). As such the presented health pathway has not yet been subject to cost-benefit analysis to demonstrate financial impacts of delivery (or not) of tailored maternity services delivered at unauthorised encampments, coupled with a case-by-case decision making process on whether to evict households from unauthorised sites which can itself impact on health outcomes and access to care.

The health pathway presented in this discussion, consisted of a maternity 'narrative' concerning a nomadic (homeless) Traveller woman, and the human, fiscal and long-term health costs of failing to deliver interventions to a woman experiencing domestic violence and a high-risk pregnancy, in a timely and tailored manner. Ultimately, money which could be saved with more positive outcomes is therefore spent in dealing retrospectively with the consequences of lack of health interventions for Gypsy/Traveller communities.

In subsequent comments and discussions Ms Jones reiterated again the importance of using asset-based community development models (ABCD) in bringing about attitude shifts in professionals, leading to actual and measurable change in public service design and delivery. She referred participants to the innovative three year asset based community development project currently being undertaken by LeedsGATE which is funded by the Lankelly Chase Foundation (the philanthropic trust who hosted the expert seminar). The project focuses on the use of ABCD and co-production techniques to influence health and public service engagement and delivery models. See further: http://www.leedsgate.co.uk/2014/06/20/abcd-project-evaluator-opportunity/#more-2310

Gabriela Smolinska-Poffley, (RSG Deputy Coordinator and Roma Support and Engagement Programme Leader, Roma Support Group (RSG) detailed RSG's history as a Roma-led, London-based civil society organization which has worked with migrant Roma populations (initially only in London but now in all localities) from all country of origins since 1998. They do not work with English Gypsies or Irish Travellers. RSG share the funding problems outlined by other civil society agencies and the struggle to balance providing much-needed services which are funded on a short-term basis. RSG have delivered a combination of policy and front-line services for 12 years, having grown from an advice based drop-in service in London. They deliver cultural competence training to experts in various locations in the UK and also work to support families who (for example) may be in contact with social services departments. They work in a number of fields to support Roma, including health, access to education, youth offending interventions, advice and access to welfare benefits, housing issues, and have always had a role in delivery of support in accessing health advice. They also support health services and other agencies in gaining cultural knowledge about Roma communities and have supported Joint Needs Assessments to ensure the inclusion of Roma needs.

She stressed that empowerment and ensuring the wellbeing of Roma in supporting access to services is a key aspect of all of their work. The majority of their service users and clients are Czech, Slovak and Romanian Roma typically experiencing problems with access to services. Clients often lack understanding of how access works, have limited understanding of how living conditions impact on health (SDOH) and what they are entitled to.

In relation to accessing health services and providing information, RSG has a role in providing support in front-line situations. Many subjects relating to maternal care cannot for cultural reasons be discussed in mixed gender groups; for example antenatal care, after-birth care. In addition there are age-related taboos with regard to what can be spoken of in front of people of different age parameters. There are also some health problems which cannot be discussed in public (or even privately), and many Roma will not willingly speak about health. Often they don't have the language

to have such discussions (both English, and the health literacy language or understanding of terms which are required to speak about medical conditions).

There are significant barriers to accessing medical care leading to on-going treatable conditions, some of which impact on women's health; reproductive issues and children's wellbeing. For many migrant Roma there is a lack of knowledge of services particularly as they come from different cultures and countries which do not have free at the point of delivery medical care. Many clients have not experienced access to medical services in their country or origin and don't know how to access it, or realise that it is free of charge.

Romanian Roma have been found to particularly lack access to medical care as a result of failure to understand that it is a free service and that they could register with GP practices. Even when they are aware of this they often require support in registration and access to health care as there are language and communication barriers. Typically service users have to communicate with the doctor in their second or third language which will not be Romanes but Polish or Slovak, and communication often takes place through poor quality interpreters who do not understand Romani culture or languages and who may not have the skill to explain terminology and culturally 'translate' questions and responses.

RSG find that their clients will often be asked to bring a family member with them to translate in health care situations. Children often have better English than parents, but use of family members impacts on ante-natal care, for example, as women can't speak in front of male relatives with regard to such matters. This has a knock-on effect and impacts on how and when women access maternity services. In addition, many Roma women don't access ante-natal care until very late or shortly before birth, which reflects expectations, circumstances and experiences in their home country.

RSG have found that Roma women often don't understand ante-natal procedures, the purposes or series of appointments. Even if volunteers and staff educate people in what to do and where to go they are frequently impacted by system changes which means that community knowledge is out of date and education on maternity services or health advice for pregnant women has to start again leading to confusion. When Roma move between cities or even London Boroughs they also have to understand the difference between methods of service delivery in different areas which can be problematic and confusing or lead to failure to continue care. Once a family become used to one area they know the system but then they move and have to learn different routes of access or find that some support or translation services may not be available.

There is also a huge lack of trust between many of their clients and health professionals who deliver services. This is because overwhelmingly Roma have been used to discrimination in their country of origin. This is frequently enacted by public services (see literature cited above) including health services. As such there is often a fear of contacting or approaching public services and people seen as officers of the State. Clients often report a fear of those in power and their greatest fear is that their children will be taken into care. There is also a good level of community knowledge of cases in which 'health neglect' (frequently associated with the issues above) has led to social work interventions over children, exacerbating the fear of

having contact with health workers. Often therefore there is a desire to avoid services and people seen as representatives of authority.

When considering how to overcome barriers to health literacy and access to services, Ms Smolinska-Poffley stressed that health services are not effective in engaging with Roma nor tailored for Roma clients. There is a need not to change how Roma behave in accessing services as much as a requirement to adapt services in partnership to meet the needs of clients, a theme which had been prominent in earlier presentations and discussions. She provided an example of good practice in children's health outreach.

A health visitor in the London Borough of Redbridge, an area with a large Roma population, was aware that although there was a visible Roma population they saw very few children and mothers engaging with health care. The health visitor initiated (with support from her line managers) street outreach, speaking to mothers to increase awareness of services. Flexible delivery of immunisations subsequently occurred as she and her colleagues were able to build trust and meet with women – sometimes being invited to their homes and then other women would also visit to receive health advice and immunisations for their children. In that way immunisations were delivered cost-effectively in a place and way which suited client needs. Immunisation uptake 'rocketed' amongst the local Roma population as well as increase in awareness of other health services.

Overall she emphasised the need to ensure that services are culturally competent and that health staff receive training in this issue. There is also a burning need for improved communication on health promotion. This can be effectively delivered by health professionals working in partnership with civil society agencies and communities. RSG clients express a keen interest in knowing how to improve the health of their children, issues such as healthy eating etc. but delivering this information requires engaging appropriately in a manner which enables Roma mothers to feel comfortable in accessing information (see above re cultural taboos on some discussions in mixed or age-blended groups). When RSG was funded to deliver health projects (short-term funding now finished) they delivered health promotion, children's health and healthy eating workshops to Roma in their community offices where service users were comfortable to attend sessions.

She ended by noting that a rising number of social work interventions were triggered by 'medical neglect' concerns. On occasion social workers reported that Slovak families refused to engage with 'parenting classes' but on discussing the issue the RSG found out that parents were not aware that they were being offered classes or what these entailed as they thought 'parenting classes' was an acronym for sex education on how to have/not have children. This feeds back to translation and cultural awareness issues, health literacy and awareness of the type of services which exist or do not in countries of origin. After having the term 'parenting classes' explained there was considerable demand from Roma parents to participate in such activities. Similarly there is no conception of the idea of 'healthy diet' in the Romanes languages and limited engagement with the idea in countries of origin. Accordingly Roma translators had to find new ways of explaining the idea of a 'healthy diet' to service users who found such concepts unfamiliar. In conclusion Ms Smolinska-Poffley stressed the need for Roma health advocates and partnership working between clinical commissioners, front-line health staff and civil society organisations to deliver appropriate, tailored services which deliver change.

Recommendations

Delegates broke into a number of groups to discuss the presentations and exchange information on both front line practice experience of the provision of advice on health care rights and access issues where this impacted on maternal and child health as well as contemplating challenges and solutions to service delivery. A number of participants are actively engaged in working in policy formation or programme design in the UK or international context (Hungary, Ireland or participating in European advisory panels) so were able to reflect upon the challenges inherent in funding issues, the particular focus of certain projects and where and how priority targets and fiscal regulations might impact on the design, take-up or GTR community engagement with particular aspects of health delivery. Following discussion the small break-out groups then reconvened and provided feedback and recommendations.

This model was repeated in subsequent workshop sessions throughout the day. Recommendations were then refined, agreed and finalised during subsequent breakout groups, within the plenary session at the end of the day, and as a result of the follow-up emails, evaluation document and survey activities circulated to attendees prior to production of the report.

RECOMMENDATION TWO

At the UK specific level it was agreed that there is a critical and urgent need for topdown leadership in relation to Gypsy, Traveller and Roma health which emphasises enforceable equalities duties in relation to the populations, and monitors and enforces clinical commissioning groups and strategic health and wellbeing boards' (HWBB) engagement with the health of the communities. As such there must be accountability at HWBB level to ensure that inclusion health priorities are embedded into their activities.

While to some extent the commissioning of services will follow hard evidence of health inequities experienced by the populations (which will arise with ethnic monitoring of health conditions and disproportionate disease burden) it is important that there is a clear and monitored expectation that Joint Strategic Needs Assessments will include the health of Gypsies, Travellers and Roma and will take account of available best evidence on the populations within a locality and the SDOH which impact them. Commissioning of targeted services should follow guidance such as that issued by Inclusion Health (2013) on best practice in practical steps for commissioning inclusive joint needs assessments and services for Gypsies, Travellers, Roma and other 'inclusion health' priority groups: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/28778 7/JSNA_and_JHWS_guide_-_FINAL.pdf

There is a need at both policy and practice level to explicitly link Inclusion Health priorities into 'person centred care' <u>http://www.institute.nhs.uk/qipp/joined up care/patient centred care.html</u> as a tool for reducing multivariate inequalities experienced by the communities.

Given the importance of sustainable, joined up working to improve the health of Gypsy, Traveller and Roma people, and the real risk of loss of institutional knowledge and individual expertise when projects are only funded on a short-term basis, it was agreed that there is an absolutely critical need to ensure long-term funding for civil society agencies to engage on health related activities, delivery of cultural competence training, health advocacy and participate in training of community health workers. In addition their work on the co-production of both research and health promotion activities must be supported. Operating in a climate of short-termism is exhausting and demoralising for staff and creates insecurity amongst service users and clients.

While it is recognised that strong and enforceable guidance in relation to local-level health inclusion of GTR populations coupled with monitoring of health need will ultimately mean that commissioners and health and well-being boards are forced to take on board the health needs of the above communities, which will in turn permit of through-flow of funding to civil society organisations who co-produce and deliver services to GTR population, there is a need for access to a sustainable funding stream to support initiatives (similar to the DH Pacesetters or Inclusion Health board funding which has now come to an end).

RECOMMENDATION THREE

Dedicated core funding must be made available for civil society 'grassroots' health projects which are driving Inclusion Health initiatives on the front line. Such projects comprise outstanding levels of expertise coupled with in-depth cultural competence and co-production of activities, health promotion materials and holistic delivery of support which address the SDOH impacting on the communities.

To ensure that there is through flow of practice based knowledge, sharing of good practice and policy, and regularly updated information on on-going and proposed research which emerges from on-the-ground monitoring of the situations of Gypsy, Traveller and Roma populations, it is important that meetings and dissemination flow occurs regularly.

The review of literature and policy (above), and discussions which took place within this and subsequent workshops demonstrated that there have been infrequent toplevel meetings at the UK level pertaining to GTR health matters (largely because of the lack of a NRIS and reliance on the MWG 'commitments' which refer to health) and that such meetings as have occurred were often in relation to specific projects or initiatives (i.e. Inclusion Health funded projects where participants may or may not have been familiar with other on-going work across the UK).

It is therefore critically important (a point made in written feedback by a number of delegates) to ensure that research is rooted in and relevant to practice and emergent

evidence of need and that to ensure utilisation of low-cost effective models (e.g. the immunisation outreach projects detailed above) and to minimise replication of less successful models at a local level, regular information sharing and monitoring of the UK wide picture is required at a high level.

To this end there is a need at the UK level for regular specialist GTR health meetings which refer to on-going activities in the field and influence multi-agency good practice with the communities across the SDOH. Whilst the following recommendation impacts across all areas considered in the thematic meeting, it has been embedded into this element of the report as a result of discussions over concerns pertaining to 'working in silos' and loss of institutional knowledge as projects are funded on a short-term basis.

RECOMMENDATION FOUR

There is an urgent need to establish a Gypsy, Traveller and Roma Inclusion Health Advisory group with assistance and membership from NHS England; Public Health England; the Faculty of Homeless Health and the Department of Health. Similar Advisory boards should be constituted across devolved Governments (Wales; Scotland and Northern Ireland unless NI prefers to continue working on an 'all-Ireland' basis as is evidenced so successfully in relation to the All-Ireland Traveller Health Report (2010).

The Gypsy, Traveller, Roma Inclusion Health Board must ensure substantial and meaningful representation from across civil society agencies working with the GTR populations and should take account of 'inclusion health' activities undertaken in relation to other vulnerable priority groups (e.g. homeless people, sex workers, vulnerable migrants etc). Funding for travel should be provided to meet the expenses of civil society organisation delegates so as to enable attendance at such meetings. The Health Inclusion Board should also host a virtual platform (with linkages to relevant forums and agencies such as the Roma Health Network; WHO and Council of Europe) to enable discussion, sharing of good practice examples, research examples etc.

The Board should work across a number of common strands pertaining to issues of health access; breaches of Equality Act legislation and identifying good practice, policy recommendations etc. It is critically important that account is taken of the changing pattern of health inequalities experienced by the diverse communities and those with whom similarities exist (e.g. increasing vulnerability of 'boater communities' without access to secure moorings) as well as monitoring activities such as patterns of commissioning of services; inclusion of GTR populations in joint needs assessments and representation on HWBBs etc.

Good practice guidance and policy on commissioning of services for 'Inclusion Health' priority groups was issued by Royal College of General Practitioners in 2013 (Gill et.al., 2013)

http://www.rcgp.org.uk/news/2013/december/~/media/Files/Policy/A-Z-policy/RCGP-Social-Inclusion-Commissioning-Guide.ashx Agreed practice based recommendations (below) in relation to maternal and child health were largely transferable and important to all forms of health promotion and protection considered throughout the remainder of the thematic meeting:

RECOMMENDATION FIVE

In devising interventions and engaging with community member around issues of maternal and child health (including access to ante-natal care; immunisations etc.) there must be a clear commitment to and expectation of co-production and the involvement of community members, peer health mediators, civil society organisations etc.in design of materials (e.g. immunisation leaflets); and activities, to ensure cultural competence and accessibility. An asset-based co-production model must be the default approach in all services targeted at GTR populations.

It is critically important to ensure that health professionals receive cultural competence training in engaging with the communities and are alert to the reproduction of stigmatising concepts, language and perceptions when relation to GTR populations. Cultural competence will include knowledge and strategies for engaging with gender-practices; language barriers etc. and awareness of specialist resources which can be utilised to support service users from the above communities.

Health promotion activities (e.g. infant nutrition, health eating, obesity avoidance etc.) can all be built upon foundations gained in engaging in issues about which there is confidence in community 'buy-in' e.g. all families want to ensure the health of their children and that women have safe child-birth experiences.

There should be an expectation that health promotion activities as well as the delivery of specific interventions or activities should involve community-facing activities (e.g. delivery of workshops in community group settings; innovative practice such as 'street-outreach' on immunisation matters etc.

Activities require investment in existing structure (people; resources; cultural knowledge and taking time to engage with communities. This can be in conflict with target cultures in the UK but it is necessary to be supported in diverting from particular methods of 'doing' and time scales to enable processes to be developed and understanding built. For example, there should be scope to enable booking of double or triple time for appointments at GP surgeries or ante-natal or child health clinics to enable time to reach understanding about concepts or permit of (appropriately skilled) translation to occur to find a common language (health literacy language as well as and shared 'common tongue') when discussing new or difficult concepts.

It was also stressed by delegates that when developing services and engaging with health care commissioners and HWBB's it is important to emphasise the 'proportionate universalism' approach to health service design and delivery so as to avoid discourse arising on 'problem' communities or perceptions of unfair use of precious health assets. This is particularly pertinent in relation to services delivered to Roma populations who are subject to additional negative stereotyping as migrants as well as members of the Gypsy, Traveller and Roma populations and for whom particular access barriers exist (particularly linguistic and sometimes lack of understanding of health care systems), over and above that experienced by Gypsy and Traveller populations.



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Workshop Three: Accommodation Issues and the Impacts on Health and Wellbeing of GTR Communities

Introduction

This workshop consisted of two papers which considered the impact of accommodation on Gypsy and Traveller health in the UK. It has been recognised in numerous publications that there is a direct link between accommodation and health care of the communities. For Gypsies and Travellers who live in caravans (believed to be approximately one-third of the population, with two-thirds now resident in conventional housing - see further Cemlyn et. al, 2009), there is a clear link between access to 'authorised sites', which are safe from eviction and provide residents with the potential to register with medical services, and the ability to achieve at least some measure of health improvement. For those community members who are technically 'homeless' through having no place at which they can legally station a caravan (see Greenfields, 2010; Cemlyn et. al., 2009; Matthews, 2008) health outcomes are widely recognised as being significantly worse. Greenfields with Lowe (2013) found evidence of a majority of Gypsies and Travellers living at unauthorised encampments in one regional area experiencing discriminatory responses when seeking to register with medical practitioners including derogatory comments being made about their 'muddy' footwear or a refusal (against legislation and policy) to

register patients who do not have a 'fixed address'. That study also noted that health professionals reported concerns over engaging with Gypsies and Travellers at sites, reporting both lack of cultural competence and fear. Nomadic Gypsies and Travellers are also less likely to have access to a range of preventative services or contact with civil society organisations able to provide advocacy and advice, impacting further on their ability to access care (Cemlyn et. al., 2009).

Supporting Literature

There is no known literature pertaining to the accommodation related health of Roma migrants to the UK although there are occasional comments in health needs assessments and reports on the service needs of Roma migrants (e.g. Brown et al. 2013; Craig, 2011; Moore, 2010) which suggest a preponderance of Roma migrants are living in over-crowded poor-quality housing which impacts on their health status.

A substantial literature exists in relation to the lack of adequate site provision for Gypsies and Travellers and the impacts for homeless or nomadic households of evictions which may disrupt medical treatment (e.g. Clark and Greenfields, 2006; Parry et. al., 2004; Cemlyn et. al., 2009; Matthews, 2008 etc.). The Inclusion Health /Aspinall (2014) report on data gaps suggested that accommodation status has perhaps the greatest impact on the health on Gypsy/Traveller communities, drawing this conclusion from the research cited above.

The subject of the health impacts of unauthorised encampment and health access for nomadic communities is inextricably linked to the UK planning system which is complex, undergoing substantial and rapid change and is subject to considerable policy scrutiny by the Department of Communities and Local Government, a UK Government department which holds overall responsibility for accommodation issues, planning matters pertaining to Gypsy and Traveller sites and community cohesion (https://www.gov.uk/government/organisations/department-for-communities-and-local-government and category search within the website) https://www.gov.uk/search?q=Gypsies))

In this report and policy recommendation document it is not possible to go into the changing legislation, numerous legal challenges (including at the European level and within domestic courts) and policy approaches to Gypsy and Traveller accommodation issues but the following documents and links will provide background information on the complex and contested issues of human rights, and duties and responsibilities for local authorities to facilitate access to Gypsy and Traveller sites which GTAAs (accommodation assessments) have repeatedly demonstrated as the culturally appropriate accommodation of choice for large numbers of Gypsies and Travellers in the UK (Clark and Greenfields, 2006; Richardson, 2007).

Abundant evidence exists from GTAAs and targeted research with housed Gypsies and Travellers which indicates that a large percentage of such 'housed' families make the transition into conventional housing from caravans to avoid repeated evictions from 'roadside' sites; or to ensure adequate medical treatment and access to care for household members experiencing poor health or disability (Greenfields, and Smith, 2010a; 2010b; Smith and Greenfields, 2012, 2013; Greenfields, 2013; Cullen et al., 2008).

Despite the focus on accommodation related inequalities experienced by Gypsies and Travellers there has been a relatively paucity of focus on the direct impacts on accommodation on their health. The noticeable exceptions to this trend consist of Parry et al.'s 2004 research on behalf of the DH which found that housed Gypsies and Travellers reported worse health than did those on sites, with depression being considerably worse amongst those who had moved into housing from caravan accommodation. The authors concluded that travelling, even if only in relation to vacations and for the purposes of attending horse fairs and other cultural events, appeared to offer a protective factor to the health of Gypsies and Travellers.

Cullen et al., (2008) and Greenfields and Smith (op. cit., various dates) all found substantial evidence of depression and anxiety amongst housed Gypsies and Travellers typically associated with isolation, loss of community, experiences of discrimination and difficulties transitioning from living on caravan sites and amongst a close knit community into the relative isolation of housing in a potentially hostile environment,, within which a substantial percentage of respondents reported experiences of racism and discrimination in accessing public services or in various social settings. Greenfields (2013) and Greenfields and Smith (2013) found particularly gendered aspects to the isolation experienced by housed Gypsies and Travellers which was explicitly linked by a number of respondents to mental ill-health which had the potential to impact on household functioning and intergenerational wellbeing. GTAA evidence and findings from the studies above all report a clear link between lack of adequate access to Gypsy and Traveller caravan sites given the shortage of supply and 'near impossibility' of leading a nomadic life in the light of repeated evictions and lack of access to services, and a 'push' for Gypsy and Traveller populations to move into conventional housing.

As such a vicious circle, driven by a policy neglect and accommodation shortage, exists, in which lack of culturally appropriate accommodation and a young and growing Gypsy and Traveller population pyramid (estimated population growth at 4% per annum, see further Cemlyn et.al., 2009) requires community members to move into housing (with potentially negative mental health impacts see above). Many respondents who moved into housing reported that they had no desire to do so and for many they had never before experienced such accommodation, leading to problems over adjustment, difficulties with literacy associated with tenancies, engaging with service providers and budgeting etc. The alternative is often to live in over-crowded authorised sites (where planning permission permits of such an option and does not place a maximum number on caravans), or at dangerous unauthorised or roadside locations with low or no access to health, education and other services, thus decreasing the health status of community members as SDOH impact on wellbeing of households which will often include young children.

A research study (currently awaiting publication by Inclusion Health/DH) which considered the inter-relationship between policy, accommodation quality, environmental health and physical and mental well-being of Gypsies and Travellers on sites (largely excluding the experiences of housed individuals unless reference is made to previous housing experience) was produced in 2014 by Greenfields and Brindley (forthcoming 2015). The content of the first presentation below (by Matthew Brindley. Policy Officer at the Traveller Movement) draws upon some themes emergent from that project.

Seminar Presentations

Matthew Brindley (Policy Officer, The Traveller Movement: TM) commenced by describing the work of the Traveller Movement as a policy, research and capacity building organisation who work with Gypsies, Travellers and Roma. Front line services are not delivered by TM although they have designed and delivered women's health advocacy (particularly around maternity care), community development and youth capacity building programmes. TM has been closely involved in the Inclusion Health programmes advising on a number of projects. In addition TM was commissioned to undertake a piece of work which looked at the impact of accommodation and the living environment on physical and mental health (see above). Matthew provided information on the long-standing work undertaken by TM in relation to accommodation and planning. After summarising the literature on the link between accommodation and health he outlined the process by which TM were asked to produce policy guidance on this issue for Inclusion Health. The commission was to include some degree of primary qualitative data gathering, an exercise which was further expanded to include physical descriptions of environments which could impact on health.

The final report is currently awaiting publication and the summary below provides an outline of its key findings.

The aim of the report was to develop a better understanding of how the living environment of Gypsies and Travellers on sites has had an impact on their health. The report took a social determinants of health approach, influenced by the Marmot Review (2010).

Matthew presented a summary of key statistics from UK government departments on the 'caravan count' and numbers of caravans resident at the four different types of site (unauthorised development; unauthorised encampment; private site and public (local authority) site. Overall around 60% of Gypsies and Travellers live in housing. The most vulnerable members of the community are those living at unauthorised encampments (often roadside sites) with minimal access to services and no security of control over when and whether eviction will occur.

A number of case studies were then presented, including an in-depth review of the 'environmental degradation' occasioned by the Dale Farm eviction of 2011 and a discussion on health impact evidence emerging from the large-scale eviction. Other

cases studies included private authorised sites, local authority sites and 'tolerated' sites.

The presentation considered narratives of loss of facility and discussed health outcomes and reported conditions of residents at different types of site. Overall, based on this research and census data, Gypsies and Travellers experience worse health, at a younger age, than do other minority ethnic communities and they are more likely to be providing care for family members than are other mainstream and minority communities. A relatively large proportion of the sample reported suffering from anxiety or depression with those in the most insecure accommodation experiencing the greatest level of poor mental health.

Significant numbers of respondents reported experiences of racism and discrimination particularly in relation to applying for planning permission for a private site. While there is evidence that over time as site residents become known to surrounding populations and become more actively involved in community activities discrimination decreases, they still experience exacerbated rates of discrimination, which impacts on wellbeing.

Evidence was provided on the environmental impact and quality of different types of site (by the categories detailed above) and how this relates to self-reported wellbeing. He concluded by explaining how poor access to accommodation is bound up with experiences of racism and discrimination in the planning system and in public discourse, which then further exacerbates anxiety and reduces health further.

Professor Margaret Greenfields (IDRICS, Buckinghamshire New University) presented a summary of findings from the extensive series of research studies she and Dr David Smith, (University of Greenwich) have undertaken collectively and separately in relation to the well-being of Gypsies and Travellers in housing, cultural retention, experiences of discrimination, access to employment, accommodation preferences and routes into housing. David Smith was unfortunately unable to be present for the thematic meetings as a result of university business which required him to attend meetings at their international campus. Greenfields therefore presented on behalf of both authors. The findings of the series of studies have been published as a single volume (Smith and Greenfields, 2013). In addition certain elements of the research have been released in journal articles (see above).

Overall the data used to inform the series of publications drew upon over 700 cases (with each case representing a household) gathered through work on GTAAs as well as findings from a series of focus groups carried out in three discrete case study areas). Across the combined study a number of key health variables were analysed. The presentation given at the thematic meeting focused on the gendered mental health impacts of 'enforced' residence in housing for Gypsies and Travellers.

In total 40% of those included in the data set entered housing due to a lack of authorised sites and/or stopping places whilst 10% did so following a failure to achieve planning permission to set up a 'self-provided/self-funded' private site. It is

worth noting that the variation in success of applications for Gypsy and Traveller sites when compared with 'mainstream' planning applications (for example to build a house) demonstrates discrimination and differential outcomes with an eight fold difference in the success of such 'mainstream' applications when compared to those for accommodation for Gypsies and Travellers. On average 54% of applications to build a Gypsy or Traveller site were granted permission (often on appeal) between 2007-2010.

Twenty one per cent (21%) of respondents entered housing after being accepted as homeless (dwelling in a caravan but no legal place to put it) and as such responses made frequent reference to being 'powerless' and forced into housing. This played out in increased rates of negative social /mental health consequences. A further 20% of respondents indicated that they had moved into housing as a result of family reasons (often referring to education or health or moving into housing to provide care for an elderly or disabled relative who was no longer able to live in a caravan or travel). The remaining 9% of respondents indicated a variety of reasons for moving into housing varying from 'always wanted to try it' to multiple and sometimes complex reasons associated with employment, relationships with a non-Gypsy or Traveller, conflict on site, etc.

A constant theme which emerged across all sources of data was a sense of 'unfairness' and discrimination against Gypsy and Traveller traditional lifestyles which precluded the ability to live in a culturally appropriate manner on a secure caravan site with access to services. Significant evidence was found of lack of contact with non Gypsy and Traveller communities with over 70% of participants of all age ranges reporting a lack of meaningful social contact/communication between their family and surrounding (non-Gypsy/Traveller) populations. In fact little variation was found in this element of the study between housed or sited families and whether resident in a locality on a long-term or short-term basis, indicative of lack of bridging capital and barriers to engagement across communities.

Respondents referred repeatedly to concerns over 'mixing' with non-Gypsies and Travellers as a result of conflicting cultural values and concerns over racism or discrimination. Over 60% of respondents indicated they had experienced financial difficulties and/ or a decline in income following the move into housing, increasing the stress of living amongst non-Gypsy/Traveller communities with whom they typically had little contact. Support services (where available) were reported to be rarely accessed due to anticipation of prejudice (i.e. non-use of services which could provide advice in relation to housing repair, welfare benefits or debt advice).

Women reported particularly negative impacts of making the transition into housing, As isolation from family coupled with cultural expectations which limited time spent outside of the home and predominantly required that socialising should occur in single-gender groups of relatives, was at odds with many 'mainstream' opportunities for meeting new people. Thus even if concerns over racism were overcome to the extent that women felt able to socialise with neighbours etc. female respondents reported that they were often limited in their activities as a result of cultural expectations and caring responsibilities.

Female respondents resident in housing reported increased rates of depression and 'nerves' when compared to those resident on sites. This was linked explicitly to experiences of housing and a perceived loss of 'culture' and was also highlighted in relation to evidence of increasing rates of drug/alcohol abuse emerging in housed populations (predominantly although not exclusively amongst men). For many respondents, discussion on substance misuse was coupled with discourse on the breakdown of extended family and patriarchal systems of social control which could lead to concerns over young people's behaviour and a risk of increased contact with criminal justice services. Breaches of expected gendered behaviour amongst young women (for example wishing to choose their own non-Gypsy/Traveller boyfriend) were regarded by mothers as particularly stigmatising and impacting on the whole family's reputation. Women's sense of isolation and depression was exacerbated by the loss of company of family and friends and some correspondents associated male retreat into use of alcohol (often associated with depression) as a trigger factor for domestic violence. Experiences of family breakdown or inter-personal violence were more traumatic as respondents commonly linked this to loss of known support networks "who can you go to talk or for a cup of tea, you can't just knock on the door of a trailer [caravan] if in a house"

Negotiating demands of administrative agencies and practical impacts (budgeting, literacy, racial discrimination etc.) were compounded by the unfamiliar physical layout and design of housing with a sense of claustrophobia being reported fairly commonly by newly housed respondents. Overall there was a recognition amongst respondents of high levels of untreated/undiagnosed Mental Health needs amongst the community but the stigma of acknowledging conditions and concerns over access to treatment and cultural competence of health professionals impacted on seeking help "*most of the women I know they are on the pills – but the doctor and nurses do just want to get rid of us – handful of pills and go away – and they don't understand what it is like for us losing your family, losing your culture"*

Greenfields concluded by noting the 'ticking time-bomb' impact on GTR mental health of enforced housing policies and a lack of cultural awareness of the needs of community. She called for the need to engage across multiple domains to reduce excessive rates of mental illness/depression across the populations and ensure equitable access to culturally appropriate, co-produced and delivered interventions to support individuals at risk.

Recommendations

Delegates agreed that there is a clear requirement for public top-level acknowledgement and closely monitored policy drivers to ensure effective joint working at local level in relation to GTR accommodation needs. Such practices represent the most effective way of reducing health inequalities resulting from poor and insecure accommodation as well as mitigating the financial and human cost of poor quality or insecure accommodation experienced for the communities.

RECOMMENDATION SIX

With specific reference to the UK context it is critically important that there is top down guidance to ensure collaborative working between local authorities and Health and Wellbeing Boards (HWBB) so as to collaboratively address the negative impact of accommodation insecurity on Gypsy, Traveller and Roma physical and mental health.

Accommodation related mental health issues need to be given greater priority in health policy and professional discourse and there is a requirement that psychological wellbeing is emphasised by civil society agencies and health advocates within community discussions. Awareness-raising activities (health literacy) pertaining to the health impacts of insecure or poor quality accommodation should also embed awareness of mental health issues and increase knowledge of culturally accessible resources such as the Traveller Movement DVD on seeking mental health support (aimed at Gypsies and Travellers). Additional relevant resources for health professionals (and service users) include FFT's publications on depression and the report of their wellbeing consultation with clients, and the report from the RSG Mental Health Advocacy project with migrant Roma http://romasupportgroup.org.uk/wp/wp-content/uploads/2011/08/Roma-Mental-Health-Advocacy-Project-Evaluation-Report.pdf

In relation to the shortage of site provision for caravan dwelling Gypsies and Travellers and the negative effects of repeated eviction or insecure accommodation there is a need to urgently review accommodation policy in the light of the equality 'duty to cooperate' and the health equity duties placed on the Secretary of State. Health policy should be embedded into all housing and accommodation policies with the intent of reducing the health outcome gap. There is a need for a system-wide analysis of cause and effect on Gypsy, Traveller and Roma health with careful attention paid to issues of accommodation.

There is a critical need for the Department of Communities and Local Government (DCLG) and Department of Health to collectively and collaboratively engage around health and wellbeing of GTR communities given the overlap of concerns and duties in relation to health; well-being and engaging with SDOH; community cohesion (in the light of wide-spread public and media hostility to 'unauthorised encampments') and reducing the human and social costs of accommodation related exclusion. Appropriate and effective inter-agency working will also reduce fiscal costs pertaining to health service delivery to Gypsies and Travellers living at unauthorised encampments (see above under maternal and child health) and to local authorities faced with eviction and 'clean-up' expenses.

DCLG, the Local Government Association and other relevant bodies including local authorities should promote the use of Negotiated Stopping Places (tolerated stopping places at suitable locations which permit Gypsies and Travellers to access health care and education) based on the model successfully piloted by Leeds Gypsy and Traveller Exchange (LeedsGATE) and Leeds City Council. Use of such options are both low-cost and effective in reducing community tensions and ensuring access to services including much needed health provision: http://www.leedsgate.co.uk/2013/11/25/negotiated-stopping-versus-transit-sites-whats-the-difference/

In relation to Gypsies and Travellers resident in housing who do not wish to live in

such accommodation there are both mental and physical health benefits to such residents of supporting self or local authority provision of sites and a freeing up of conventional accommodation for households in need of houses who would not consider or tolerate living in a caravan.

Concerns were expressed over the environmental health and living conditions which pertain on not only unauthorised 'roadside' sites which may be in highly dangerous or polluted areas, but also some publicly owned, local authority sites on which Gypsies and Travellers rent 'pitches'. The following recommendations therefore address the issue of responsibility for ensuring decent standards of accommodation for tenants at such locations.

RECOMMENDATION SEVEN

Local authorities should take immediate steps to improve the living environment on local authority Traveller sites so they meet the standards set out in the Government guidance on 'Designing Gypsy and Traveller Sites':<u>https://www.gov.uk/government/publications/designing-gypsy-and-traveller-sites-good-practice-guide</u>

Local Planning Authorities (LPAs) should, as routine, engage Clinical Commissioning Groups or Health and Wellbeing Boards when reviewing planning applications for Traveller sites so as to ensure that provision conforms with Planning Policy for Traveller Sites (PPTS) and the National Planning Policy Framework (NPPF) requirements to promote healthy communities. A NPPF and health and wellbeing available from the Town Country Planning checklist is and Association:http://www.tcpa.org.uk/data/files/TCPA FINAL Reuniting-healthplanning.pdf

In the light of the almost non-existent information pertaining to Roma housing circumstances despite persistent anecdotal evidence and comments from civil society organisations working with communities of appalling housing conditions, it is critically important that a SDOH approach is taken when reviewing the health status of Roma households. The inclusion of a discrete Roma category in ethnic monitoring data for health, housing and other public sector agencies will permit of a more granulated and nuanced understanding of the housing situation and impacts on health of accommodation experienced by Roma migrants.

RECOMMENDATION EIGHT

There is an urgent need to commission and undertake research into the housing circumstances and impact of poor quality accommodation on Roma physical and mental health. The impact of such housing issues is relevant not only at individual and public health levels but also (see Workshop Three) has implications for social care interventions in relation to children and families.

There is a need to engage closely with the Faculty of Homeless Health; Inclusion Health; DH and DCLG as well as civil society organisations and local authorities in relation to mapping the housing circumstances of Roma migrants to the UK.



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Workshop Three: Social Work Engagement with GTR Communities, Good Practice and International Concerns

Introduction

This workshop signalled a shift of focus from health to 'social care' and in particular the emergent issue of social work engagement with Gypsy, Traveller and Roma families. The focus of the session was specifically on social work contact and interventions in relation to child protection issues although it was clear that there was scope for significant other areas of discussion including knowledge of social care rights, access to support for families caring for disabled relatives etc.

Although presentations again focused predominantly on the current situation in the UK where there has been a significant increase in child protection interventions in relation to GTR communities in recent years (see supporting literature and summary of Dr Allen's presentation below), consideration was also given to the European dimension of this trend, in the presentation by Dr Leggio on emergent findings from the on-going EC funded multi-national MigRom project led by Professor Matras of Manchester

<u>http://romani.humanities.manchester.ac.uk/migrom/background.html</u> within which Roma experience of migration and contact with public services are a central feature of the project. Overall the workshop on child protection and social care attracted perhaps the greatest amount of discussion and it was extremely difficult to bring the session to a close as the relative paucity of interest (to date) in the subject of social work engagement with GTR populations in the UK (and Europe more widely) has led to limited opportunities for practitioners, civil society actors and policy professionals to collectively discuss a subject which has largely been anecdotally observed at a local level by support agencies, but which has not been subject to wider comprehensive scrutiny despite the clear synergy between GTR inclusion, the SDOH and social work contact with families. Whilst Cemlyn (see further below) has undertaken a significant body of research into social care agencies' contact with and attitudes towards Gypsies and Travellers in the UK, to date there has been a dearth of evidence pertaining to the experiences of Roma migrant populations and limited recognition of the similarities of experience between Gypsies, Travellers and Roma service users, in relation to social work engagement.

The publication (after this thematic meeting) of the final report of the RomaMatrix project (Brown et.al. 2015, <u>https://romamatrix.eu/research/final-research-report</u>) has added to the discussion on this subject as that report includes a section on children in the public care system in various Member States including the UK (see supporting literature below).

It was abundantly clear that there was considerable scope for at least a full day conference on this topic and indeed subsequent to this thematic workshop (prior to production of this report) there have been two separate one-day events on this subject held in the UK: one at the University of Salford (emerging from the RomaMatrix study https://romamatrix.eu/events/gypsy-roma-and-traveller-childrenand-care-system) and the other at the University of Manchester (funded by the EARNS http://www.coe.int/t/dg4/cultureheritage/culture/romastudies/2015/OJ-<u>Safeguarding-Roma-Children-2502.pdf</u>) with the latter bringing together international academics and practice-based experts working on this subject including from the European Roma and Traveller Forum and the Roma Support Group. The panel at the Manchester event convened by Professor Matras and Dr Leggio, included Professor Greenfields and Jenni Berlin who discussed an on-going pilot project being undertaken with a number of delegates at this thematic meeting. The University of Salford event which was linked to the final report of the RomaMatrix project (see above) was co-convened by Dr Allen and featured findings from the RomaMatrix project as well as community experts (including delegates who participated in this thematic meeting) who presented on their work or experiences of contact with social care agencies in relation to child protection concerns¹¹.

Supporting Literature

As noted above there has been relatively little policy or research attention paid at a national or international level to Gypsy, Traveller and Roma contact with social care agencies. Other than a multi-national report compiled by the European Roma Rights

¹¹ Contact Dr Dan Allen or Professor Phil Brown, University of Salford and/or Dr Viktor Leggio or Professor Yaron Matras for further information pertaining to these events.

Centre in 2011 and recent emergent data from the RomaMatrix report (2015) few publications have drawn attention to the transnational nature of Roma overrepresentation in child protection cases. Research into this area is as with many other subjects of interest bedevilled by lack of routine ethnic monitoring at member state level despite persistent anecdotal evidence of a European wide trend (see further Allen, 2015, forthcoming).

It was only from 2009 with the adoption of extended ethnic monitoring coding that children of Gypsy or Roma ethnicity, or those of Irish Traveller heritage could be disaggregated from other statistics on children in the public care system in the UK. In many member states such identification is still not possible within social care datasets although based upon limited available research (above) and persistent anecdotal report there is a significant over-representation of Roma children who are subject to public care, frequently as a result of interventions occasioned by poverty and neglect, or poor housing and health conditions, associated with social exclusion and discrimination. In addition, in a substantial number of EU member states official policies and social work practice existed up until the 1970s which explicitly sought to remove children from Roma families to 'educate' them in such a manner as to 'eradicate' ethnic identity, the use of Romanes as a language and Roma cultural practices (Cemlyn & Briskman, 2002; Vanderbeck, 2005; Liegeois 1986; ERRC, 2011)

Dr Sarah Cemlyn (co-author of this report and a delegate at this thematic meeting) is responsible for by far the largest and most consistent body of work pertaining to social work engagement with Gypsies and Travellers in the UK. In the late 1990s she undertook large scale research into English social services departments' policy and provision for Gypsy and Traveller children and families. Cemlyn (2000a, 2000b) found that only a tiny minority of social services departments had specific policies relating to Gypsies and Travellers and these overwhelmingly focused on guidance pertaining to undertaking assessment of children and families which could mitigate implementation of eviction policies for nomadic households.

As such the social work policy focus on GTR populations framed them as a 'problematic community' with social work professionals' role linked to eviction proceedings, rather than seeing the communities as falling within a wider constituent group of families potentially in need of support and empowerment. (More widely within social work, poverty, exploitation, poor housing conditions, racism, stigmatisation, community conflict and lack of access to services are seen to undermine family stability and resilience, and increase risks to family life see further Jack and Gill, 2003. As outlined earlier in this report, these negative factors significantly impact on Gypsy, Traveller and Roma families). Garrett (2004) found that whilst 42% of a sample of local authorities in England reported delivering services to Irish Travellers only three (4%) of the sample detailed positive engagements with the remainder linking assessment of need to the local authority role in implementing evictions of 'unauthorised encampments'.

Greenfields (2002; 2006) has also carried out research into the experience of Travellers' engagement with family law systems and the outcome of enquiries made by social workers in relation to nomadic families. Greenfields (in analysis of legal data sets and qualitative research undertaken with court welfare officers, solicitors and families impacted by family law proceedings) found disproportionality in the use of 'prohibited steps orders' when compared with 'mainstream' family law and child protection cases, with respondents indicating that such orders were often issued when concerns were expressed that a child could more suitably be raised in a house than on a site. Social work intervention in that study was found to be frequently triggered by concerns over a child's attendance at school and/or 'inappropriate adult responsibilities' including involvement in tasks associated with living a nomadic life and engaging in work-related tasks from a young age.

There is considerable evidence of lack of contact and trust between social services professionals and Gypsies and Travellers (Cemlyn, 2000a, 2000b, 2006; Greenfields, 2002, 2006, 2008; Power, 2004, Allen 2012). Research findings repeatedly emphasised that suspicion of social services by families is based on the fear of children being removed into care.

Indeed this widespread association between any form of social work contact and child protection issues is a clear and emergent theme within reports and casework based evidence provided by front line civil society actors working with Roma in the UK and wider Europe (see literature cited above, and the presentation given at this meeting by the Roma Support Group). A fear of 'removal' of children has therefore become embedded into cultural 'knowledge' held by Gypsy, Traveller and Roma people. Engagement with social workers is feared to the extent that civil society agencies report that child protection enquiries may not infrequently be met with resistance by families to the extent of relocating (particularly for Roma and Irish Traveller households) to another European country (i.e. return to country of origin or from England to Ireland and vice versa) or leaving a house and becoming nomadic or moving from one site to another, so great is the concern that discrimination against GTR populations and social workers' lack of cultural knowledge will automatically lead to children being removed into care even when support services and interventions could mean that significantly different outcomes occur.

There is evidence that children moved into public care are overwhelmingly placed away from their own cultural context given the limited number of Roma, Gypsy and Traveller foster carers with inevitable negative impacts for their identity-based wellbeing and in some cases loss of adequate communication given the fact that Romanes is unlikely to be spoken in mainstream society households. Cemlyn et al (2009) and Allen (2015) report on the lack of foster carers from GTR communities who could provide cultural continuity to children placed away from their families, and there are believed to be even fewer social workers of Gypsy, Traveller or Roma heritage. Greenfields (2008) found that young Gypsies and Travellers in the UK believed that social work was a stigmatised and stigmatising profession amongst their communities as it was automatically associated with child protection and 'taking children away'. One Irish study into the targeted recruitment of Traveller foster-carers for Irish Traveller children in care found significantly better outcomes than when children were placed in a culturally 'alien' environment (Pemberton, 1999). This is borne out by Allen's doctoral research and follow-up practice based publications (Allen, 2012; Allen & Adams/BAAF, 2013). Allen's doctoral thesis which grew from his experience as a social work practitioner consisted of a review of the experiences of Gypsy and Traveller children in the public care system in the UK and Ireland, focusing on the impact on identity and self-perception of stigmatisation and racism experienced in out-of-home care settings. He is currently engaged in on-going follow-up research.

The high level of discriminatory media attention and word-of-mouth dissemination of information pertaining to high profile removals of children into care in a number of countries arising from (wrongful) trafficking concerns at the time of the 'Blonde Maria' case and other similar incidents in 2013/2014 (McGarry, 2013 <u>https://www.opendemocracy.net/can-europe-make-it/aidan-mcgarry/romaphobia-last-acceptable-form-of-racism</u>) have further exacerbated fear and mistrust between Gypsy, Traveller and Roma families and social care professionals.

Cemlyn et. al. (2009) http://www.equalityhumanrights.com/sites/default/files/documents/research/12inequa lities experienced by gypsy and traveller_communities a review.pdf provide (at section 5.1 pp125-135) a thorough review of all existing literature pertaining to Gypsies and Travellers in the public care system and social work engagement in the UK published up until 2009. To the best of our knowledge Allen's more recent work (Allen, 2012, 2013) comprises the only publications on this subject published since the EHRC review took place in 2009. Allen has since worked with the British Agency for Adoption and Fostering (BAAF) to produce a good practice guidance pack on working with GTR families in child protection cases (Allen & Adams, 2014).

A small-scale on-going pilot research project into Roma experiences of contact with youth offending teams and social work agencies (with particular reference to child and young peoples' protection concerns) which consists of qualitative data collection from Roma migrants, an online survey and focus group activities with support workers who have acted as mediators or advisors for Roma clients involved in child protection cases and an on-line survey of social workers is currently underway in Manchester, Derby and London¹² and is expected to report in early Autumn 2015.

Key themes which have been identified in the limited UK and European research into social work engagement with Roma families have borne remarkable similarities. Chapter Six of the RomaMatrix final report which summarises evidence from 10 European member states involved in that project (Brown et al, 2015) emphasises the complex interplay of material poverty, poor environmental health and housing and accidental injury associated with poor living environments (and see Workshop Two findings). While the authors suggest that there have been recent policy drivers in some member states which seek to reduce institutional care as an option for children, they still suggest over-representation of Roma amongst children living away

¹² Contact <u>Margaret.Greenfields@bucks.ac.uk</u> for further information

from home although in both Spain and Poland a tendency exists to place children with extended family members avoiding loss of cultural continuity. They stress however that children living in non-family care often seem to do less well as a result of isolation from culture and community and lack of awareness of training on Roma culture.

Findings from this element of the report also suggest that there is a relatively widespread pathologisation of Roma culture amongst social work practitioners with an oft-commented assumption that material deprivation is related to Roma 'culture'. The report emphasises the need for culturally sensitive social work training, a roll-out of successful initiatives (such as in Hungary) which have led to increased foster carer recruitment amongst Roma and greater resource allocation to both engage with and support families having difficulties, as well as to mitigate the impacts of social exclusion, poverty and related issues. While member states typically indicate that a child should be reintegrated into their community as soon as possible, the report provides a number of examples taken from member state case studies which reflect upon the lack of support for care leavers creating a situation which means that reintegration back into the Roma community can fail, leaving a young person isolated and at greater risk of vulnerability than before. Whilst the report provided examples and initiatives aimed at supporting families and a general trend towards de-institutionalisation (i.e. greater reluctance to place children in large care homes), the point was made that there is often a mismatch between rhetoric and practice with limited resources or policy engagement with the issue of Roma children in public care.

Findings from a review of existing European-wide literature on social work engagement with GTR communities (prepared in relation to the on-going UK research by Buckinghamshire New University, Universities of Derby and Manchester) has identified the following themes as core to studies in various member states: stigmatisation of Roma; pathologisation of Roma culture; lack of appropriate or adequate translation services; lack of trust; social work professional staff not being reflective or representative of the client group served; GTR communities hiding concerns or problems as a result of fear of children being removed into care; lack of mutual understanding and collaboration between professional agencies and NGOs in relation to support for GTR communities.

These themes are also beginning to emerge within the on-going UK study into migrant Roma experiences in relation to social work practice, and have been found in (as yet unpublished) research carried out into the attitudes and cultures of social workers in Italy working in Roma settlements (Ulderico Daniele) and with social workers in Switzerland working with Roma street youth (Iulia Hasdeu) presented at the EARNS funded seminar in Manchester, UK in February 2015. As such it would appear that there are common themes and trends visible across a number of member states in relation to this area of practice.

Presentations

Dr Dan Allen, University of Salford and a qualified social worker, presented on social work engagement with Gypsy, Roma and Traveller communities, good practice and international concerns. He commenced by reflecting on the role of front-line social workers (SWs) and stating that a decision to intervene in children and

family cases is difficult. The threshold for intervention is based on legislation and interpretation of policy but also subjective experiences and decisions on what is 'good enough' parenting. It is therefore a value judgement to some extent.

Having summarised the legal routes, timeframes for action and options (Children in need or Child at Risk of Harm) in the UK context (a decision and assessment results in differing services and actions) he stressed how the current climate and pressures/cutbacks means that predominantly it is children seen to be at risk who receive services or interventions and children in need often get very limited universal service support. He reflected back on the dangers of cultural and linguistic misinterpretation explored in presentations (see example from Gabriela Smolinska-Poffley of the RSG who explained how parents thought that they were being offered 'sex education' rather than parenting classes and thus refused the support. This led to their being identified as non-compliant by social workers, which could have had serious consequences in terms of assessments and recommendations made. He stressed that there is a great need for being aware of cultural variability in work and the risks of errors in translation, both translation of meaning and of cultural or professional knowledge.

Diverting into a consideration of whether SWs are engaged in 'care' or 'control', Dr Allen expounded on the impacts of poor accommodation, unauthorised sites, overcrowded accommodation, parents experiencing mental health issues or poverty and difficulties with language or access to education. However these are also found in other communities and individuals with whom social workers engage so there is a problem in terms of how Gypsies, Travellers and Roma are viewed rather perhaps than the situation. SWs are aware of principles but this can be masked by a sense of lack of knowledge of a culture. When someone feels a 'cultural stranger' and uncomfortable this can impact on how risk is assessed whether through lack of knowledge or prejudice. GTR families are at risk of being pathologised and disempowered through coercive interventions. Conversely, cultural relativism can impact in not acting when there is a need to do so, as can be seen in Serious Case Reviews (undertaken when a child dies under the watch of a social work team). These issues are illustrated in a serious case review following systematic failings with an Irish Traveller family in Southampton http://www.westsussexscb.org.uk/wpcontent/uploads/2014SouthamptonFamilyAOverview.pd

Dr Allen referred to the lack of data in the EU context on GTR children in the public care system and noted that it is only in the last few years that it is possible to review statistics on GTR children in the UK. The numbers of GTR children in care have gone up dramatically between 2009-2014 (last available figures). There is an increase of 350% for Roma/Gypsy children in the care system and 200% for Irish Traveller children. Anecdotally the large increase is accounted for by migrant Roma children whose circumstances were often very difficult prior to migration in relation to issues around poverty, linguistic barriers, lack of medical care in country of origin etc. Figures however are homogenised and collated together although there involve very different cultures and former circumstances.

In December 2014 he noted there was a report that the Department for Education was seeking to find new ways of engaging with families of children at risk yet despite the increase in GTR children in the care system they were not mentioned in that communication and thus institutionally ignored.

Although there are no clear data on Roma children in care in Europe, it appears likely that the lack of ethnic monitoring allows on-going lack of discussion about their situation which is also a form of institutional racism. Ethnic monitoring figures are not kept across most of Europe but the ERRC found in the 2011 report that Roma children were grossly over-represented in care homes. The research was undertaken by asking children in care and staff about ethnicity. In Hungary for example, Roma account for 7% of the population but 65% of children in care homes. Once in a care home it is a 'life sentence' as racism and discrimination mean that foster or adoptive carers (who are themselves almost never Roma) will not accept a Roma child. As such Roma children are discriminated against on multiple levels.

In Dr Allen's own research into children's experiences in care in the UK and Irish context he found that children were glad to be safely protected from abuse where it occurred (e.g. violence of substance abusing parents) but they reported that the cultural trauma and discrimination they experienced in out of home settings was worse than the situations they'd left. They were institutionally abused through being placed with non-Gypsy/Traveller families with no cultural awareness. The UK Government's shift away from expectations of placement with families of the same cultural or religious background to rapid placement has and will worsen this situation given the lack of GTR foster carers.

He stressed the need to undertake co-production of social work research and materials with communities to enable the understanding of the impacts of care and harm on GTR children. It is difficult to talk about taboo subjects such as neglect and abuse but it is critical to work with communities. Dr Allen concluded by saying he had intended to speak about the award-winning Haringey model of Community Social Work in which they work in partnership with Gypsies and Travellers but as Michael Ridge was present at the workshop he would ask him to speak instead on his team's practice. In conclusion, Dr Allen also introduced the fact that although it is at an early stage, an international association of social workers working with and from Gypsy, Traveller and Roma communities is being developed to assist in policy and practice development.

Mr Michael Ridge Lead Community Social Worker from the Haringey Travelling People's Social Work Team spoke briefly about the model of work undertaken by his team. He commenced by saying that they were fortunate to work in a statutory sector environment using a community social work model and that they were probably the only such team left in the UK. Community social work was popular in the 1970s and 1980s and was part of social work training but is no longer taught and is a rarity in practice.

Community Social Work models utilise the concept of partnership working and coproduction to bring about empowerment and collaboration. He suggested that social work and social workers have a dreadful reputation amongst Travellers and in most cases are associated purely with removal of children. However his team are engaged in partnership with communities, work in community settings, engage in inter-agency forums linking social workers with housing officers, health practitioners, youth offending teams and people planning services targeted at Gypsy, Traveller and Roma communities. As such they can offer input and engage community members with a range of services. Community social work involves deliberate strategies of empowerment and he sits on advisory panels with the London Gypsy and Traveller Unit and is a Trustee of the Traveller Movement as well as involved in events such as Gypsy Roma Traveller History Month¹³. The needs of GTR communities in his area are therefore represented in joint needs assessments and Gypsies and Travellers become engaged and enter into community forum events and act as advisors themselves, being mentored and supported and engaging in partnership work with the social work team.

Mr Ridge (who was present at both thematic meetings) noted that in the crime and policing event there was discussion about whether the police are a 'force' or a 'service' and he noted that the same issue pertains within social work: i.e. whether SWs are engaged in caring or controlling. He noted that cuts to services and the loss of community social work models are also associated with increased marketization and different philosophies of social work in the current climate. Noting that when the community social work team was under threat of closure there was community engagement by Gypsies, Travellers and Roma and that the communities lobbied to keep the service, he cited this as evidence of community empowerment and engagement. As such their voices had to be heard by those in positions of making policy. Mr Ridge strongly advocated such a model of social work practice as effective in working with GTR communities in a holistic manner and one which could be effectively replicated in other areas of the UK and across Europe.

Dr Viktor Leggio of Manchester University (MigRom Project) outlined the MigRom project. It is an FP7 funded five country study (France, UK, Italy, Spain and Romania) exploring the migration pathways and the experiences of engaging with public sector services of Romanian Migrant Roma. He briefly outlined how the study builds upon earlier work undertaken by Manchester University in partnership with Manchester City Council in relation to developing innovative outreach to newly arrived Roma in the city. The original project had involved Manchester university staff (Professor Matras and Dr Leggio) working with Roma to explore their needs and issues and then reporting to the city on what was required. A key finding was that Roma migrants' needs were no different from those of other migrant groups, housing, employment, health and access to services being key themes. Roma migrants lived in diverse multi-ethnic areas and reported very little racism as they 'blended in'.

The initial piece of research found that there was a desperate need for translation services into and from Romanes and in the MigRom project a community engagement and development strand was therefore built into the project from the outset. A number of Roma migrants were trained to act as community advisors and

¹³ Gypsy, Roma Traveller History Month also known as GRTHM (note the order in which the communities are listed rather than the more commonly used GTR history month) is an initiative which takes place across the UK every June to showcase and celebrate Gypsy, Traveller and Roma culture and history. It has been strongly championed and supported by specialist 'Traveller Education' teachers from conception as a way of challenging racism in school settings. Modelled on the international 'Black History Month' initiative which was conceived of a way of ensuring that Black people were included in curricula and achievements and histories of Black people were acknowledged and celebrated; GRTHM has taken place since the middle of the last decade with diverse events occurring across the UK supported by local Government, educational and cultural organisations and civil society. For the history of the event and information of the diverse events which take place see: http://grthm.natt.org.uk/whatis.php

translators to bridge the gap between mainstream services and the Roma population. In addition to the academic research strand of the MigRom project there is therefore a collaborative outreach and drop-in service jointly supported by Manchester City Council. Two Roma development officer posts have been created and a drop-in service is available to local Roma. The trained and employed staff also act as role models for younger Roma migrants and bridge the gap between generations as many older Roma were lower on skills and training than the young people who have been resident in the UK for some years now.

Roma in Manchester now know about the service and it has expanded in terms of capacity and dates when available. If staff are unable to provide direct advice on a particular issue they know who to refer the service user onto and can provide appropriate translation services to assist with engagement. There is an explicit approach of 'not looking for' service users so that there is no sense of coercion or seeking to find work to support the project. Similarly, the approach is non-holistic, in that only the issues reported by users are discussed, in order to avoid the impression of encroaching into users' private life. Roma migrants however increasingly use the drop in to enquire on issues such as housing, CV writing support, access to employment (which has increased as a field of work since employment restrictions on A2 migrants have been lifted), information on health care etc. A report of the enquiries dealt with can be found types of here: http://romani.humanities.manchester.ac.uk/migrom/docs/MigRom%20briefing%20Oc t%202014.pdf.

In contrast to this community engagement practice (which has also been used on a long-term basis by the Roma Support Group) which normalises and moves away from stigmatising or pathologising models of migrant Roma behaviours, Dr Leggio provided a case study of how discourse and statistics can be used to create an inflated sense of 'otherness' which feeds into developing specialist targeted services. In 2013 in the wake of child sexual exploitation concerns in Northern England (particularly associated with a series of cases concerned with Pakistani male perpetrators) minutes of council meetings raised the issue as to whether Roma girls were at risk of 'early marriage' or sexual exploitation. Discussing briefly the issue of whether teenagers involved in a consensual relationship and spending time at parents houses' under parental control was any greater risk than when found in other communities, he went on to explain that subsequent local authority meetings then drew upon poorly recorded and analysed data to suggest that teenage pregnancy associated with 'early marriage' was a particular 'Roma problem'. He noted that the data provided dated from prior to much Roma migration and was in any case not differentiated by Roma ethnicity which was not appearing as a category in ethnic monitoring datasets. Accordingly, a finding of 12% of teenage pregnancies being from Eastern European families was both meaningless in the absence of whole figure data (e.g. does this relate to only a tiny number of young women) and in any event did not evidence a long-term or statistically significant rise as the data was old when considered in 2013. He noted that specialist advice was asked for by the local authority and this was provided by an agency who suggested (according to data in minutes) that there was a large problem (using the data above) and who were then provided with a grant to support Roma at risk of teenage pregnancy and sexual exploitation. In turn a safe-guarding strategy was developed by the local authority which pre-supposed, on what appears to be unsupportable and weak evidence, that Roma were a particularly high risk group in need of a particular strategy, such as did not exist for other ethnic minority groups in the locality.

Essentially therefore the case-study was illustrative of the proposal that a combination of negative and stigmatising discourse pertaining to Roma could lead to the creation of local level policy as a result of a cycle of engagement between agencies who were funded to engage with a 'problem' which they identified. Dr Leggio called for greater use of solid evidence when policy is developed, an end to short-term and 'knee-jerk' policy formation, a requirement that policy formation does not simply support an 'industry' around Roma and greater recognition of the need to engage in community partnership and development to enable access to services to occur in a mainstream manner. As such he argued that services should be made more culturally sensitive and barriers to access removed to enable Roma migrants to access services on their own terms and to suit their own needs, albeit facilitated through appropriate translation services provided by trained community members. Following such an approach removes the need to constantly invest in interventions which may not be required and which can stigmatise and pathologise service users whose needs are not essentially different from that of other newly arrived migrant populations.

The final presentation of the day was by **Dr Phil Henry, University of Derby Multi-Faith Centre (MFC),** who commenced by endorsing Dr Leggio's statement about the danger of 'industries' being created by agencies who move into working with Roma (or whichever is the current group for whom funding is available) and create a discourse of concern rather than engaging in co-production and working with populations to identify their needs and preferred models of engagement.

Having outlined the complex dynamics of the migrant Roma population in Derby who come from various EU member states and arrived at different points in time (see Dr Henry's presentation) he explained the background to the development of Roma Community Care, a semi-autonomous University supported NGO which employs Roma staff and volunteers and is actively engaged in the co-production of engagement with public services and policy makers.

He explained that the MFC which is politically and religiously neutral has a lengthy history of working with diverse (often excluded) local communities in a manner which embeds community engagement and community development practice. Some four years ago they were approached to support work with migrant Roma communities who were regarded as hard to reach and in need of provision of services. Dr Henry detailed the terms of engagement with the local Roma community at that time, indicating that as Director of the MFC he agreed that his team would only engage with the project if they could bring about positive change and if they were not the right organisation to undertake the work then they would not wish to become involved in activities in case they caused harm or could not meet the needs of the population.

The Roma 'gate-keepers' to whom the MFC staff were introduced came however from a Pentecostal background and were eager to ensure that space was available for worship for their community, creating an immediate space for dialogue and shared understanding given the remit of the MFC. From these initial beginnings and a development of understanding of the needs of the local Roma community the MFC collaborated with local Roma on developing work which is still on-going four years later. He noted that their model of practice has 'broken down barriers and opened doors with agencies to enable them to engage productively with Roma communities who had previously not used or engaged with services such as health, youth work, probation etc. Although youth services are in significant decline and have recently been cut throughout Derby, the MFC employ two youth workers. As a result of ongoing discussions and partnership working with the community, who expressed a need and desire for targeted youth work, the MFC and Roma Community Care jointly provide diversionary youth work with Roma which offers a wrap around and holistic model for engaging and supporting young people and their families.

Speaking about the way in which some agencies lose interest when 'money runs out' Dr Henry noted that two out of three voluntary sector community partners left their collaborative project with Roma to undertake different things whilst the third was funded to engage across communities. The MFC felt 'morally obliged' to continue supporting the local Roma community and Roma Community Care and in his role as Director of the MFC Dr Henry was able to continue allocating support for a further 18 months until Roma Community Care accessed some funding. Although they were not aware of the Manchester model described by Dr Leggio, MFC/RCC are carrying out similar work "working with Roma to support Roma not doing to Roma". Their outreach and drop-in services have increased to several mornings a week and their youth work to three evenings a week. They undertake 'connective outreach' and are engaged with the Derby equivalents of inter-agency Forums as discussed by Dr Leggio and Mr Ridge, supporting and enabling community, statutory and voluntary sector agencies to become involved with delivering accessible services to the local Roma population of approximately 4000 people living across two or three wards. Since the adoption of this holistic model and intensive engagement in community forums and inter-agency activities by RCC and MFC there has been a flow of placements and secondments from statutory sector agencies and services (including health, youth offending, social work etc.) to work with RCC, thus enhancing communication between and across agencies and between Roma community members, community advocates and service providers.

The following section of the presentation involved fairly raw confidential data provided by the local safeguarding board and as such cannot be reported in full. The difficulties noted elsewhere in the workshops on lack of access pertained in Derby in terms of identification of households under stress as they were monitored largely under the broad terms of White Other 'Central European' (out of 17 identified populations). However based upon discussions and assessments the broad brush picture of issues which had led to social work attention were as follows: neglect, domestic violence and parental substance misuse.

Approximately 9% of children in need or child protection cases involved Central European households although by far and away the greatest number of cases (over 60%) in both categories consisted of children from White British households.

RCC and the MFC work with a network of Slovak and Polish Roma volunteers who engage with case-workers to support Roma households in contact with social workers. This ranges from culturally appropriate explanation of processes and terms to translation. There is far more than simple translation required to enable communication to occur. Dr Henry provided examples of translators being asked to work with Roma but without having the right dialect to communicate. Now using the RCC/MFC network this difficulty has essentially evaporated. RCC/MFC have supported approximately 50 households in relation to child protection/children in need cases. Mainly of these involve parental 'neglect' and typically (as explained by several speakers including the Roma Support Group) this pertained to medical neglect, poverty, lack of understanding of concepts interpreted as non-compliance, housing related concerns and children being 'neglected' through parents working at night or leaving them with other non-household members.

A key area of misunderstanding was that parents felt if a young person or child was living in a house or road amongst other Roma who would to some extent all be related or connected then 'we are all looking after them'. Social Worker claims of neglect were treated with great indignation as there was an assumption of whole community support and non-relatives who look out for a child even if the parents were absent working and/or the child was in a neighbouring house. The mismatch in conception of 'good enough parenting' and expectations of adult care of children by being present in the same premises at all times was especially problematic, particularly as Roma parents felt that a neglected child was one who had the freedom to go 'into the town' on their own or be out without family guardianship (see further Greenfields and Smith, 2010 for a discussion on similar concepts amongst Gypsy and Traveller communities).

When social workers were in contact with families there was also a comprehension gap caused by lack of literacy and different ways of telling narratives (see Helen Jones' presentation above) so that there could often be a 'meaningless' exchange where social workers felt that a Roma family had understood what was said and would 'comply'. When they did not, this was treated as non-compliance. In the face of authority figures, and in the light of previous experiences of discrimination in countries of origin or fear over engaging with social services, it was a common finding that Roma families related in a 'passive' manner which was taken to mean understanding and agreement rather than bewilderment or lack of understanding of instructions. Social Workers would then leave feeling that they had done their job without realising that there was a communication gap. Dr Henry stressed too that many Roma families whom RCC supported in child protection cases had absolutely no concept of what was occurring in the sense of assessments. Social workers (or support workers, as little distinction was made between the different staff) were perceived of as people who assisted with food vouchers or helped with accommodation and it was therefore a shock to realise that a parenting assessment was being made during visits. Concerns frequently arose over the fact that corporal punishment and domestic violence incidents were not seen as outside of normative behaviours by a number of community members who came into contact with social work practitioners.

Dr Henry also noted that given the lack of Roma foster carers and the fact that there is less stress on matching a child's placement by culture or ethnic/religious background following guidance changes (see Dr Allen's presentation), Roma families whose children were in trans-national and sometimes inter-ethnic placements experienced a very real distress about the shift of cultural environment. Parents reported particular distress over a child being placed in a home where foster carers followed a different religious denomination or faith. Dr Henry concluded by reiterating the call for cultural competence amongst social workers and inter-agency, collaborative working driven by agencies which included staff from the communities they serve.

Discussion and Recommendations

The discussion from this final workshop of the day draws together a number of themes which are common to earlier sessions.

Within the UK there is often a disconnect, made worse by reduced funding to social care services and top down bureaucratic regulation, between the aspirations of social policy and its actual implementation. This can apply across the board with all population groups, particularly when the groups most often in receipt of social care services are those in poverty and poverty and inequality have been exacerbated over recent years through the approach taken to deficit reduction (e.g. benefit cuts and sanctions for those already on the lowest incomes and in the most difficult circumstances).

However for groups who are even more marginalised on other grounds also, notably through racism, the disconnect between social care policy and practice can be even greater. This is true for Romani Gypsies and Irish Travellers, and for Roma who have come to the UK more recently from Central and Eastern Europe.

This disconnect is in no-one's interests, since it can lead to more costly service provision e.g. children entering the care system when other provision could have supported them to stay with their families, and trauma and loss for children and families themselves. It therefore needs to be urgently addressed by policy makers with policies that are underpinned by sufficient resourcing and sufficient grasp of what is effective.

RECOMMENDATION NINE

There is a clear need for disaggregated ethnic monitoring across all European member states to establish a clearer picture of the numbers of Gypsy, Traveller and Roma children (by discrete ethnic category given the varying circumstances and needs of each of the three communities) within the public care system. Such monitoring should take account of the under-lying drivers for entry into care so that it is possible to assess to what extent lack of social inclusion and appropriate models of engagement are implicated in this assumed disproportionality.

NRIS monitoring reports should include information on the situation of Gypsy, Traveller and Roma children in the care system as well as measures taken (including a drive to recruit foster carers from such communities) to reduce such care and to enable (where it is safe and possible) children to be returned to their communities and families of origin.

The following set of good practice recommendations pertain specifically to social work training and practice

RECOMMENDATION TEN

There is a critical need for the adoption of community social work practice (such as is outlined in Michael Ridge's presentation and that of Dr Phil Henry) to enable holistic support and care to be provided to Gypsy, Traveller and Roma community members at risk, as well as enabling communities to share their strengths, develop mutual trust, and participate with services in promoting the wellbeing of children and families and enabling capacity and knowledge-building to occur within agencies and community settings. Community advocates who can help bridge the gap between services and communities should be embedded into child and family social work engagements

It is critically important that social work training and curricula re-embed concepts of community social work and that social workers in contact with GTR communities are offered access to high-quality co-produced resources and cultural competence training and work in partnership with civil society organisations in delivering support to the populations. All social work training programmes and professional workplaces should provide sufficient grounding in cultural understanding and sensitivity, developed through a reflexive approach framed by political, sociological and cultural understanding of the context of people's lives. Without such training, families may be pathologised, resulting in unnecessarily coercive intervention, or a failure to provide services when these are required

It is essential to enable professionals to work flexibly where bureaucratic guidelines (e.g. re time limits for assessment), simply do not otherwise allow enough time and scope for communicative engagement and sharing of understanding and transparency, or to enable families culturally unfamiliar with British systems to be able to learn about and appreciate the aims of professional social work and support.

Where children do need to be safeguarded there is a need to prioritise and enforce the requirement to seek extended family or friends care wherever possible, accompanying this with the provision of support and resources to the alternative carers, including the provision of culturally appropriate accommodation if needed.

Work must be undertaken to increase the development of fostering among Gypsy, Traveller and Roma communities so that where children do need to be safeguarded by entering the care system, there is more possibility of culturally relevant and appropriate alternative care being provided.

Wherever care is provided, there needs to be a sustained focus on enabling GTR children to develop a secure cultural identity. Cultural continuity must become a centralised feature of any care planning process.

One key element of the concluding debate which was regarded as worthy of being highlighted was the absolute requirement that service delivery should be offered in a non-stigmatising and non-pathologising manner which recognises Roma as being a migrant community who may require access to services in the same manner as other recent migrant populations, rather than an especially vulnerable or 'suspect' group presumed to be particularly associated with deep poverty, trafficking, child neglect and criminal activity.

This point draws upon the recognition that there is sometimes a sensationalised international focus on perceived trafficking of Roma women and children (see too the report from the Crime and Policing thematic meeting of 3/12/14: Greenfields, James and Berlin, 2015). It is of course critically important that trafficking itself must be addressed and victims safeguarded and supported, but there must also to be much more care about assessing potential situations of concern to ensure that actions are undertaken in balanced, proportionate and professional manner. Where authorities have rushed to remove children, often publicly, only to return them to their families later when no evidence of trafficking has been found (Foster and Norton, 2012), such precipitate action has not only caused significant distress to children and families, but has increased stigmatising media discourse, and greatly exacerbated the legacy of mistrust and suspicion towards social care agencies and police services noted above and in the report of the earlier thematic meeting (Greenfields et. al. 2015, op. cit.)

RECOMMENDATION ELEVEN

Social work and support agencies must ensure that they have access to culturally competent translators and communicators who are able to ensure that 'meaning' is delivered and translated to service users rather than simply words.

It is key to ensuring understanding of processes that any materials prepared and delivery of information provided is comprehensible, culturally relevant and understood.

Holistic, wrap around services which offer access to mainstream services (and opportunities for appropriately supported learning opportunities for social care professionals) should be made available to GTR households in contact with social care agencies utilising the community development models outlined by Dr Henry and Mr Ridge.

To this end there should be sharing of good practice within member states and across member states and the proposed International Association of Gypsy, Traveller and Roma Social Work practitioners referred to by Dr Allen is to be commended. Such a network can offer both good practice information and support for social work practitioners working with the communities, whilst offering support, guidance and access to peer mentors and role models for Gypsies, Travellers and Roma considering becoming foster carers and/or undertaking a career in social work.

In concluding this section of the report explicit reference is made to the presentations on social care given above.

Conclusions

Drawing together the themes of the day and the linking discussions there is a critical need to develop a holistic national and European-wide strategy for enhancing Gypsy,

Traveller and Roma equality and inclusion in relation to health and social care. Such a strategy must be rooted in awareness of empowerment and community development models and take a SDOH approach to policy design and practice guidance whilst recognising the differences between the discrete communities (as well as individual capacity) such as to ensure that needs are effectively met rather than imposing a 'one size fits all' model targeted at all people identified within European policy documents as 'Roma'.

It is important to consider the costs and human, social and fiscal waste associated with the imposition of (or failing to implement) particular policies which impact on GTR communities and which mitigate against social inclusion; essentially those themes which are core to NRIS and which must clearly include social care and social work domains. It is proposed that there should be a fiscal analysis undertaken within and across member states which seeks to calculate the costs to society as a whole resulting from 'waste' occasioned by failing to deliver preventative health and social care services

The point was made by a number of delegates that there is a need to problematize the growth of privatisation models which militate against inclusive and pro-active community focused engagement.

A central aspect of any strategy at member state and international level is to ensure that all professionals access effective training re working with GTR, including the political, social, cultural and policy context, communication across linguistic and cultural boundaries, working with community advocates, reinforcing professional values and understanding conflicts which can arise between such values including the requirements for continuing professional registration and unhelpful policy and managerial requirements, when working with marginalised Gypsy, Traveller or Roma communities.

A community orientation in working with GTR peoples is effective in meeting a number of the challenges that have been identified throughout the thematic meeting and in supporting community empowerment, such as to facilitate partnership working in addressing these needs.

It is important to build on areas of engagement where trust can be more easily developed and to maintain relationships with communities as a foundation for dealing more effectively and positively with crisis situations.

Resources for interpretation and community engagement need to be adequate in order to avoid further costs in future in relation to both health and child protection. Cuts under austerity can be counterproductive.

Local decision making can be positive but also negative, depending on the local political context. In the main, (and using a UK example) local majorities which are already hostile to GTR people can find an increase in their power to exclude under localism policies.

Strong central direction is therefore needed in relation to promoting equality and developing cultural sensitivity to promote positive models and recognise the pitfalls of 'one size fits all' policy making. Accordingly it is important to endorse a combination of tailored service delivery and 'proportionate universalism'. One

example of such accidental negative consequences arising from policy enactments impacting the UK child protection system is the restriction of the child protection assessment process to 12 weeks, which does not allow sufficient time for engagement, interpreting, sharing and developing understanding and accurately assessing the different elements in any child protection situation. This change is anecdotally already leading to negative consequences for migrant Roma families involved in child protection proceedings pertaining to the category of neglect.

It is therefore critically important to support, facilitate and enable GTR people (at local as well as national and international levels) to input actively into both service and policy design and delivery as well as reporting on the outcomes of policy processes. Careful attention is thus needed to the impact of central policy directives not only from the Council of Europe but also those designed and enacted by member state which are often well intended but have negative unintended consequences for marginalised groups and recent migrants.

Use of a closely monitored and incremental policy-making process, which is not sclerotic such that duties and requirements are crystalised when they may potentially still be under-developed, and which permits adequate scope to review outcomes and refine and extend policy (see further Hill, 2014) so as to be 'fit for purposes' (such as have been suggested in relation to NRIS monitoring duties above) is therefore key to tailoring a holistic national and European wide Roma integration strategy.

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Additional Resources

In addition to materials available via hyperlinks within the report and those included in the bibliography, a number of relevant resources can be accessed from international agencies working with Roma people; websites of organisations and agencies which participated in this event and other networks with whom participants work. See further below for a non-exhaustive list of relevant agencies:

Council of Europe: http://www.coe.int/en/web/portal/roma

The Decade of Roma Inclusion: http://www.romadecade.org/index

Derbyshire Gypsy Liaison Group: http://www.dglg.org/health-resource-files.html

Friends Families and Travellers: <u>http://www.gypsy-</u> traveller.org/?s=health&submit=Search

The Fundamental Rights Agency: (Romani Women and access to health care: http://fra.europa.eu/sites/default/files/fra_uploads/180-ROMA-HC-EN.pdf

Leeds Gate: http://www.leedsgate.co.uk/work-projects/health/

MigRom: <u>http://romani.humanities.manchester.ac.uk/migrom/report-policy-</u> <u>briefs.html</u>

Open Society Foundation:

http://www.opensocietyfoundations.org/search?key=roma

Pavee Point: http://www.paveepoint.ie/resources/health/

The Roma Health Network: http://romahealthnet.org/en/

The Roma Support Group: http://romasupportgroup.org.uk/?page_id=58

The Traveller Movement: http://www.travellermovement.org.uk/what-we-do/policy/health-2/

Travellers Aid Trust: http://travellersaidtrust.org/

World Health Organisation: <u>http://www.euro.who.int/en/search?q=roma</u>

Participating Agencies/Experts attending the Thematic Meeting

- Susan Alexander (Travellers Aid Trust)
- Dan Allen (University of Salford)
- Katayoun Bahramian (Pavee Point)
- Jenni Berlin (IDRICS/University of Eastern Finland)
- Matthew Brindley (The Traveller Movement)
- Sarah Cemlyn (University of Bristol)
- Shay Clipson (Romany Gypsy and Traveller Consultancy)
- Janie Codona (One Voice 4 Travellers)
- Ray Earwicker (Department of Health)
- Margaret Greenfields (Buckinghamshire New University)
- Phil Henry (Multi Faith Centre, University of Derby)
- Mary Humphrey (Photographer)
- Helen Jones (Leeds Gypsy and Traveller Exchange)
- Viktor Leggio (University of Manchester/MigRom)
- Yvonne McNamara (The Traveller Movement)
- Jackie McPeak (Buckinghamshire New University)
- Zoe Matthews (Friends, Families and Travellers)
- Ruth Passman (NHS England)
- Michael Ridge (Community Social Worker, Travelling People's Team, London Borough of Haringey)
- Gabriela Smolinska-Poffley (Roma Support Group)
- Teresa Staniewicz (Centre for Rights, Equality, and Diversity (CRED), Warwick University)
- István Szilard (University of Pécs Medical School/Roma Health Network)
- Chris Whitwell (Friends, Families and Travellers)
- Jessica Wheeler (University of Cambridge/Cambridge Migration Research Network)

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Appendix 1: Welcome pack for the International Health and Social Care Seminar

International Health and Social Care Seminar Gypsy, Roma and Traveller Health and Social Care seminar 4th December 2014 9.30am – 17.00pm



This seminar is funded by The Council of Europe, the European Academic Network of Romani Studies and the Pro Vice Chancellor, Faculty of Society and Health at Buckinghamshire New University.

University of Warwick, CRED have provided financial support to enable Pavee Point delegates to attend and present on their work for which we are most grateful. The University of Derby Multifaith Centre have also provided us a significant degree of practical in-kind support in preparing for this event.

We have been extensively supported in this event by the Lankelly Chase Foundation who have most generously provided us with the venue for this expert seminar and access to their facilities.

We would like to express our sincere gratitude to all of our sponsors without whose kind assistance this event would not have been able to occur as well as to our speakers and those agencies and employers who have supported their attendance.



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Notes



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This seminar is a 'closed' session for invited policy experts, practitioners and community groups. As such whilst we will be uploading to the IDRICS website copies of presentations for interested parties who were unable to attend the event, all discussions will use simplified 'Chatham House' rules - meaning that recommendations, discussions, examples, concerns over particular forms of crime, policing etc. and considerations detailed during the workshops will not be attributed to any individual when we prepare the report and policy guidance resulting from this seminar.

This model enables attendees to discuss potentially controversial issues in a confidential setting to enable us to work together to acknowledge challenges and emergent solutions, and to enable us to seek to influence policy and steer good practice in the UK and wider European context.

All delegates will be reminded of the confidentiality inherent in participating in this event on the day. Delegates will be circulated with a copy of the draft policy guidance for comment in early Spring of 2015 prior to publication and dissemination of the report.

Photography

We will have a professional photographer present at the event to sensitively document the proceedings.

Mary Humphrey has worked closely with Gypsy, Traveller and Roma communities over a number of years and specialises in images of community life, developed in partnership with the subjects of her photography.

A consent form is included in the delegate pack. Mary will only share photographs or take pictures of attendees with permission. Any photographic images will be available to be viewed and agreed by the subjects before being published in any outputs or IDRICS publicity.





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Welcome from Professor Greenfields

It is with great pleasure that I welcome you here to today to take part in this important policy debate on Gypsy, Traveller and Roma experiences of accessing health, and engagement with social work agencies in the European context. You have all been invited to attend as individuals with significant degrees of expertise gained as front line professionals, policy experts, practitioners, academics or community members who have direct experiences of the impacts of these critically important services on the lives of Gypsy Traveller and Roma communities.

The intended outcome of this expert seminar is not merely to produce another report which can gather dust on a shelf but to work to share expert knowledge and engage with each other to bring about positive action. As such we intend to ensure that today's activities will directly impact on policy formation and influence good practice in ensuring equality of access to, and treatment by, health and social care services when Gypsy, Traveller and Roma community members come into contact with front line medics and social work staff. As individuals with familiarity with the health and social care systems we are all too often aware that members of GTR communities are frequently marginalised and excluded, or may even receive clearly discriminatory treatment when they seek contact (or are required to engage) with health and social work providers. As such this event seeks to explore both tension points and injustices and well as considering transferable best practice and opportunities for positive, evidence-based models of engagement.

I and my colleagues from the partner institutions involved in developing this seminar look forward to working with you now and in the future in this important field of policy development. We anticipate that today is simply the next stage in an on-going process of enhancing inclusion of Gypsy, Traveller and Roma communities in the context of health and social care and hope that we can collectively continue to share our knowledge to bring about positive change in the months and years ahead.

Mangut Guffil

Prof Dr Margaret Greenfields Professor of Community Engagement and Social Policy Buckinghamshire New University







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Gypsy, Roma and Traveller Health and Social Work Engagement International Expert Policy Seminar

9:30 – 10.00am	Networking and Coffee
10.00 – 10.15am	Welcome and outline for the day Professor Margaret Greenfields
10.15 – 11.00am	 Professor István Szilard, Chief Scientific Advisor WHO; University of Pécs Medical School, Hungary: <i>"Policy and Practice Challenges in improving Gypsy, Traveller and Roma Health in Europe"</i> Dr Ray Earwicker, Health Inequalities Unit, Equity and Social Inclusion Branch, Department of Health: <i>"Department of Health responses and approach to improving GRT health in the UK"</i>
11.00 – 12.45pm	Workshop 1: Maternal and Children's Health Ruth Passman, NHS England, Head of Equality and Health Inequalities Zoe Matthews & Chris Whitwell, Friends, Families & Travellers Helen Jones, LeedsGATE Gabriela Smolinska-Poffley, Roma Support Group
12:45 – 13.30pm	Lunch
13:30 – 14.45pm	Workshop 2: Accommodation Issues and the impacts on health and wellbeing Matthew Brindley. The Traveller Movement Professor Margaret Greenfields, Buckinghamshire New University
14.45 – 15.00pm	Refreshments break
15.00 – 16.30pm	Workshop 3: Social work engagement with GRT communities, good practice and international concerns. Dr Dan Allen, University of Salford Dr Daniele Victor Leggio, University of Manchester Dr Phil Henry, University of Derby/Derby Roma Care
16.30 – 17.15pm	Whole Group Discussion – preliminary agreement on key policy guidance/practice points for inclusion in report (to be finalised via email/collaborative review of draft document)
17.15-17.25pm	Close of Event/agreement on next steps (Margaret Greenfields)





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Speakers Biography

Dan Allen has been working with Gypsy, Roma and Traveller young people, families and communities for 13 years. In 2007 he secured funding from the Economic Social Research Council to complete a Masters in Social Work Research and a PhD. These two programmes of study enabled him to begin consolidating his knowledae and understanding of social work with Gypsy, Roma and Traveller groups. Whilst completing this period of study, Dan also spent some time working as a child protection social worker in the North of England. This experience provided him with the opportunity to develop a key understanding of particular. some of the challenges being faced by Roma young people in In 2011 Dan focussed his work as a social work academic and practitioner. As well as teaching social work students, he is also working to improve social work with Roma, Gypsy and Traveller children, families and communities in the United Kingdom and across Europe.

Matthew Brindley is Policy Manager for the Traveller Movement, a leading national policy and voice charity, working to raise the capacity and social inclusion of the Gypsy, Traveller and Roma communities in Britain. TM act as a bridge builder bringing community members, service providers and policy makers together, stimulating debate and promoting forward-looking strategies to promote increased race equality, civic engagement, inclusion, service provision and community cohesion. Matthew has managed and authored both large and small research projects primarily focused on bringing about policy change in the key areas of planning and accommodation, health, education and economic inclusion. He is also an experienced policy worker and regularly provides briefing papers and gives presentations to Government Minister's, shadow Ministers, the All Party Parliamentary Group for Gypsies, Roma and Travellers etc. TM has an established track record of active policy development, community engagement and social cohesion work. They were a shared award recipient of the Liberty Human Rights Award 2004 for our management of the Traveller Law Reform Project and recently awarded the All Party Parliamentary Group on Maternity care for award 2011 for their health and wellbeing project with the Traveller communities.

Ray Earwicker is a Senior Policy Manager in the Health Inequalities Unit at the UK Department of Health. Among numerous other duties within the DH, he is the policy lead for the social determinants of health, governance and international work in the Health Inegualities Unit, and the DH lead for EC Equity Action programme of health inequalities. He was the secretary to the Independent Inquiry on Health Inequalities (the Acheson report) 1997/98.

Margaret Greenfields, a Professor of Social Policy and Community Engagement at Buckinghamshire New University works extensively in the field of social inclusion, ethnicity, equalities and social justice, undertaking collaborative research with communities at risk of marginalisation, racism and 'othering'. She has worked closely with Gypsy, Traveller and Roma (GTR) communities for over 25 years as well as leading action research studies with vulnerable migrants, LGBT members of faith communities, and refugee/asylumseeking women. In addition to her membership of a number of NGO and Central Government advisory panels, editorial board memberships and activities as a funding reviewer for several agencies, she is currently engaged in a number of trans-national networks which are undertaking research and policy development in the fields of mobilities, migration and social policy and the health and social care needs of migrants and Roma.

Dr Phil Henry is a sociologist with special interests in policy, identity politics and religion. He developed his training as a researcher at the University of Liverpool exploring Buddhist social movements, activism, and minority groups in the global landscape. His research interests lie in Symbolic Interactionist methods of engagement and encounter and the nature of life as performance, and stigma as a feature of discredited identity. The theme of identity politics and the global subversion of religion for ideological and political gain resonate with his current areas of research in 'Understanding Radicalisation'. He is also committed to the empirical exploration of chain migration east west in a European context, out of which the politicisation of the Roma nation by agents of the state, and the continued marginalisation of Roma in the UK is a feature. His work on Roma and their engagement with youth offending services and with social work provision has implications for policy at home and in the wider EU context. It raises questions of human rights and cultural





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rights against the backdrop of a public and political discourse that seeks to put barriers in the way of freedoms of movement and of equality across a variety of European nations. His background in the Police service and as a researcher of the marginalised in society, includes work on deviance and difference and the challenges to policy makers of those who sit outside perceived normative social roles.

Helen Jones is the Chief Executive Officer at Leeds Gypsy and Traveller Exchange (Leeds GATE), where she has worked since the organisation began in 2003. Leeds GATE is a community led member's organisation, whose aim is to improve the quality of life for Gypsies and Irish Travellers in West Yorkshire. Prior to Leeds GATE, and whilst her children were small, Helen enjoyed a varied career in food production, horticulture and agriculture. During this period Helen lived with Gypsy people in the West Midlands. After leaving the West Midlands Helen worked as a volunteer Police Special Constable and as Traveller Family Worker at Irish Community Care in Manchester. Since joining Leeds GATE Helen has nurtured the organisation through a decade of operation. The organisation is established as among the leading Gypsy and Traveller organisations in the country, providing services to local Gypsy and Traveller people and maintaining a national profile as stakeholder to the Department of Communities and Local Government and to the Department of Health.

Helen is the author of several publications regarding Gypsies and Travellers including 'How to Engage with Gypsies and Travellers as part of your Work' which is endorsed by the Inclusion Health Board.

Daniele Viktor Leggio is Research Associate at the University of Manchester, where he also completed his PhD in Romani Linguistics. He has participated in educational project in Roma camps in Italy and conducted research with Roma in Italy and on the Internet. He is currently investigating the reactions of local authorities to Roma migrations as part of the MigRom project.

Zoe Matthews is as a Strategic Health Manager at Friends, Families and Travellers, one of the leading national organisations seeking to address and bring an end to the inequalities faced by Gypsy and Traveller communities. FFT is a membership organisation and many of its members are Travellers, or have children and grandchildren who travel.

Her expertise is in the field of Health Inequalities of excluded and marginalised people. She has written about health inequalities, particularly the chronic exclusion faced by Gypsies and Travellers

Ruth Passman is the Deputy Director for Equality and Health Inequalities. Ruth has enjoyed a diverse portfolio career spanning the voluntary, academic and public sectors, operating at Directorial and Chief Executive Level to establish and lead health renewal organisations. She has worked in the Department of Health and across government on the wider determinants of health agenda as Senior Health Policy Adviser/ Public Health Specialist. Ruth has worked at local, regional and national level promoting Equality and tackling Health Inequalities. She has been involved in formulating policy for End of Life care, the implementation of human rights in healthcare, promoting dignity and is passionate about working from the asset base of individuals and communities. Ruth strives to use a co-production approach in order to ensure that on the ground experience is translated into effective health and wellbeing policy and practice to deliver real and improved outcomes for people, places and health services.

Gabriela Smolinska-Poffley is the Roma Support Group's deputy manager and a Roma Support & Engagement Programme Leader. She has been working with East European Roma communities since 2002. From 2002 until 2005 Gaba ran after school activities for Roma children and young people. These included art and crafts sessions and a reading group; through those activities Gaba was co-responsible for the creation of Colours of Hope: A Little Book by Roma Refugee Children for Everybody, a pictorial book written and illustrated by Roma refugee and asylum-seeking children, which was first published by the RSG in 2003. Between 2005 and 2011 Gaba ran different health-related projects including Roma Health Awareness and Advocacy Project funded by the Volunteering England and Roma Mental Health Advocacy Project funded by the King's Fund; facilitating Roma refugees and migrants' access to health and mental health services and empowering them to gain a greater control over their lives. Gaba is a co-author of the Roma Mental Health Advocacy Project Evaluation Report published by the Roma Support Group in 2012. More recently Gaba has been co-running the Roma Support & Engagement Programme, which is our response to a growing need amongst service providers to ensure specialist and cost-effective interventions for Roma families across the





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UK. Through this programme Gaba supports professionals and organisations working with Roma communities across the UK. Gaba delivers Roma culture awareness training sessions, a specialist assessment and intervention service for Roma families in crisis.

Professor István Szilard is a specialist in internal medicine and public health medicine. He joined International Organization for Migration (IOM) in 1996 to participate in emergency and post-conflict humanitarian operations in the Balkans. Upon his initiative and his coordination, in 2003 IOM Budapest Mission (in cooperation with the US Embassy in Budapest) organized a Regional Conference on Public Health and Trafficking where twelve countries of the region participated, most of them at MoH level. The conference adopted the 'Budapest Declaration on Public Health and Trafficking in Human Beings'. From 2004 to July of 2007 he was IOM Senior Migration Health Adviser in charge of Europe and liaison person to EC/EU on migration health.

In 2007 Professor Szilard has returned to his home university and now he is chief scientific adviser at the Pécs University Medical School and he is heading its migrant and ethnic minority health programs. Now he is the coordinator (overall or Hungarian) of several EU level projects - among them the ARECHIVIC that is focused on assisting trafficked children. In 2010 with his coordination the University of Pécs has hosted EUPHA 3rd Conference on Migrant and Ethnic Minority Health in Europe and he is the coordinator of the consortium of six EU Universities developing the EC co-funded ERASMUS CHANCE Project: MSc in Migrant Health. In October this year he was the organizer -in cooperation with WHO - the expert level symposium entitled 'Healthy ageing of Roma communities - Endowers - Realities - Perspectives'. The participants out of eleven countries have adopted the 'Pécs Declaration' that has been uploaded on the WHO Europe website. Acknowledging University of Pécs and Professor Szilard's achievement, on the 10th of November this year WHO Regional Director Dr. Zsuzsanna Jakab has signed a Memorandum of Understanding with the University, where migrant and ethnic minority health are in the focus. Professor Szilard has published more than 120 scientific papers and he is the co-editor of WHO 'Public Health Aspects of Migration in Europe' electronic newspaper."

Chris Whitwell is the Director and Company Secretary at Friends Families and Travellers one of the leading national organisations seeking to address and bring an end to the inequalities faced by Gypsy and Traveller communities. FFT is a membership organisation and many of its members are Travellers, or have children and grandchildren who travel. Before FFT he occupied various senior posts within the public and voluntary sectors. Originally a town planner by profession, Chris has developed an increasing interest and involvement in issues around equality and social justice. In particular he calls for a greater focus on addressing the needs of those groups that are 'chronically excluded' and who frequently remain wholly untouched by mainstream initiatives aimed at choice, participation and empowerment.





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Buckinghamshire New University

Our vision at Bucks New University is to be a leading professional and creative influence, shaping higher education for the benefit of people and employers. Within a caring and supportive environment, we deliver high-quality scholarship, as well as focused research and professional practice. Our mission is to put our students first and work responsively with the very best partners to influence, inspire and nurture talent for professional and creative careers. To achieve this, we have put the student experience at the heart of all our plans. We work with a range of partners regionally, nationally and internationally to ensure that our students leave us ready for the world of work, and that we are able to meet the current and future needs of employers.

The Institute of Diversity Research, Inclusivity Communities and Societies (IDRICS) works to ensure that high-quality research and evaluation is undertaken which contributes fully to the life of communities, agencies and service providers by providing robust evidence which supports the development of effective and efficient policies and practices in the areas of diversity, inclusivity and community studies. IDRICS integrates its work across inter-professional learning which grows our capability.

The University of Warwick

In less than fifty years since being founded we've become one of the UK's best universities known as a world leader in research and teaching, and consistently at the top of UK league tables (ranked 3rd, by the Times & the Sunday Times, for 2015). We are a university that champions independent thinking and as well as being founded, first and foremost, on academic excellence, a key driver of the Warwick success story so far is our entrepreneurial spirit. A key strength is our relevance to society and our close working relationships with the government and business partners, resulting in ground breaking discoveries with academic and industry partners globally. Companies tap into Warwick knowledge to develop their own strengths and ensure they remain at the cutting edge within their industries. And that cutting edge insight is developed out of truly world class research: Warwick ranks 7th overall in the UK for research, and has 19 departments in the top ten in the UK in their unit of assessment; 65% of Warwick's research is 'world-leading' or 'internationally excellent'.

Warwick University's Centre for Rights, Equality, and Diversity [CRED], focuses on investigating a number of key themes, through research, consultancy and policy development. We examine the social and political determinants of the oppressive and exclusionary processes that deny citizens equal treatment and fundamental human rights (in particular, racism, xenophobia, Islamophobia and anti-Semitism); analysing tensions and conflict within and between ethnic and faith communities, and the implications of diversity for contemporary societies. We also develop Widening Participation initiatives for diverse groups at local, regional, and national levels, seen as key to sustainable social cohesion and economic success.

University of Greenwich

The University of Greenwich is one of the leading universities in London – the largest in the capital by student numbers, the best for teaching excellence according to The Sunday Times, the greenest in the country as assessed by the People and Planet Green League Table, and our research has been adjudged by our peers to be world leading. Our students and staff continue to win major awards, prizes and accolades for their high-quality achievements and contributions to society.

The Council of Europe

The Council of Europe is the continent's leading human rights organisation. It includes 47 member states, 28 of which are members of the European Union. All Council of Europe member states have signed up to the European Convention on Human Rights, a treaty designed to protect human rights, democracy and the rule of law. The European Court of Human Rights oversees the implementation of the Convention in the member states. Individuals can bring complaints of human rights violations to the Strasbourg Court once all possibilities of appeal have been exhausted in the member state concerned. The European Union is







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preparing to sign the European Convention on Human Rights, creating a common European legal space for over 820 million citizens.

Romani Studies EU

The overall aim of the European Academic Network on Romani Studies is to support efforts towards the social inclusion of Romani citizens in Europe. The project facilitates intercultural dialogue and raises the visibility of existing research outside the academic community in order to foster cooperation with policymakers and other stakeholders. By creating an interface between academic researchers and political decision makers, while promoting and improving the existing resources on the European Roma communities, the project shall ultimately allow for the implementation of better conceived policy initiatives based on reliable evidence.

Roma Support Group

The Roma Support Group (RSG) is the only Roma-led charity organisation in the UK. Since its founding in 1998, the organisation has assisted thousands of Roma families in accessing welfare, housing, education, health and employment, as well as empowering Roma communities through a wide range of advocacy and cultural programmes. During the last 15 years we have built a wealth of expertise on Roma issues and have become the leading experts in this field. We have developed best models of practice regarding integration and empowerment of Roma communities which has led us to become advisers to governments, statutory and non-statutory agencies nationally and internationally. Since 2011, the RSG has been implementing the Roma Engagement and Support Programme (RSEP), which enables statutory and voluntary agencies to respond effectively to the needs of Roma families by working with professionals through delivery of training and specialist advice; organising strategic Forums to share good practice; facilitating a wide range of interventions and Roma Families Support Schemes.

Lankelly Chase Foundation

Exists to bring about change that will transform the quality of life of people who face severe and multiple disadvantages. We focus particularly on the persistent clustering of social harms such as homelessness, substance misuse, mental and physical illness, extreme poverty, and violence and abuse. We employ a number of different methodologies, including grant making, special initiatives and commissioned research and policy analysis. We aim to work in a problem solving way, supporting or promoting action based on a robust analysis of both the problem and its underlying drivers. Our fundamental goal is to help shift the way that people on the extreme margins are valued by society, so that policy, public debate and practice are focused on people's capabilities and humanity.





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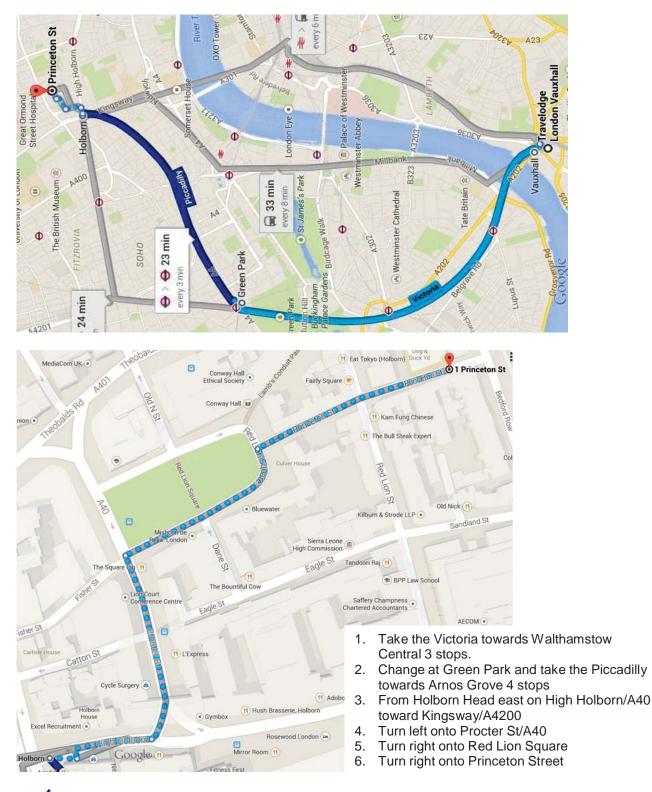




Maps

Lankelly Chase from Travelodge Vauxhall

1st Floor Greenworks Lankelly Chase Dog and Duck Yard Princeton Street London WC1R 4BH







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