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Institute for Diversity Research, Inclusivity, Communities and Society

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"Even getting through the door can be a problem if they think you are dirt":

Health consequences for stigmatised and vulnerable groups

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Outline of Presentation

- Introduction to research background
- Case studies – specific vulnerable groups
- Costs of poor quality or inaccessible care
- Staff/Service User identification of barriers to care
- Good practice in outreach
- Transferability of concepts and (partial) solutions

Research Database

- Case studies drawn from series of health and social inclusion projects undertaken by IDRICS
- Gypsy, Traveller and Roma health
- Boater health
- Refugee and Migrant Women's access to health services

Background - GRT

- Estimated 250,000-300,000 Gypsies and Travellers in Britain equivalent in size to the Sikh community (CRE 2006; EHRC/Cemlyn et. al 2009) nb: 3-4% p.a compound natural population growth = 380,000-410,000 in 2014. (Figures exclude estimates of Roma migrant populations).
- Figures for migrant Roma vary from between 50,000-200,000 (2008-2013 reports - e.g. Salford University RomaMATRIX; 2013; Craig, 2011; MigRom, 2014).
- Average life expectancy of G/T populations in the UK has been estimated variously as 10-12 years below that of 'other' White British citizens (Parry et al, 2004). Baker/LeedsREC (2006) estimated an average life expectancy of 50 years, Bedfordshire NHS Health Trust (2010) around 65 years.
- No such data exists on Roma populations in the UK although based on European reports e.g EPHA, 2014; FRA, 2012 it is anticipated that higher morbidity and early morbidity exist and that significant variations in health status may be found when Roma are compared to other 'mainstream' populations.

- 2/3rds of Gypsies/Travellers now resident in housing. Of those in caravans approximately 21% have nowhere to live/statutory homeless
- Roma overwhelming living in housing – anecdotally often severely overcrowded and poorly maintained (Craig, 2011).
- Parry et. al. 2004; Cemlyn et. al., 2009; Greenfields, (various dates) have all found abundant evidence of premature morbidity; high rates of cardio-vascular disease; over-representation in Type II diabetes; arthritis; asthma and obesity; increasing reports of problematic substance misuse and high rates of anxiety and depression.
- Craig, 2011 suggests that the limited research findings pertaining to Roma migrants offer a similar picture. See too NFGLG, 2014 – report on NRIS in the UK, health review and recommendations.

Case Study

Irish Traveller family on unauthorised encampment/repeated evictions – pregnant 41 year old (5 older children), limited ante-natal care, no screening for foetal abnormalities "*feeling unwell*". Late miscarriage approx. 24 weeks. Discharged from hospital 4/7 to 'car park' – midwife follow up care.

Temporary registration arranged with GP. Prescribed anti-depressants 8/52 as unable to cope with loss. No counselling offered, family mobile/repeat evictions.

When researcher interviewed family in relation to homelessness 5 years later, woman still taking anti-depressants, did not believe had had review.

Clear evidence of on-going psychological trauma, shaking, anxious, panting. 16 year old daughter caring for family as mother ‘unable to cope’.

Registered when possible as temporary patient in local areas and presented medication bottle/prescription sheet. Support volunteer (Catholic Chaplaincy) reported GP simply *“scribbling out the prescription couldn’t get us out of there fast enough and had initially refused to accept the woman until I went with her. No blood pressure or history taken.”*

Family functionally illiterate, no awareness of risk of long-term medication use reported 2/3 attempts to register with GPs turned away as no vacancies, outside area or don’t deal with Travellers site.

- Reanalysis of large scale data sets reveals approximately 70% of nomadic/insecurely sited G/T households refused primary care.
- "*They tar us all with the same brush – see us as dirty Gyppos"*
- "***Even getting through the door can be a problem if they think you are dirt… we come off a site - unauthorised so it was muddy - and I was in boots - my son was ill he is part-deaf, autistic and has breathing problems and I carried him in and the receptionist said you're leaving mud on the floor - "have you come off of that Gypsy site – I think you want the other surgery we don't have your people registered here." My son couldn't breathe well and I just wanted to see the doctor and she wanted me to take my boots off outside of the door***"

The Boating Community

- "*homelessness on water*".
- Dramatic increase in 'continuous cruisers' 2007-2014 (3,200-5,400) [Canals & River Trust, 2014] compared to 9% decrease in leisure craft/permanent moorings
- 2/3rds without home mooring moving an average of 12 miles per month
- To date IDRICS study (2013 http://bucks.ac.uk/content/documents/Research/INSTAL/703398/B_NES_Health_Study_Report_FINAL_%28Full_report_Inc_Appendices%29.pdf jointly commissioned by BANES local authority and BANES Health Authority the only known health survey of this population (see below).

- BANES study suggests that whilst families with (generally young) children and young single people are represented amongst continuous cruisers there is an over-representation of divorced/single middle-aged males in the population.
- Major self-identified health issues consist of alcohol/substance misuse; bronchial problems; sensory impairment (eyes/hearing); muscular-skeletal injuries; depression/anxiety and sharp injuries/trauma associated with engines/equipment (hatchets etc.) falls/broken limbs on icy tow-paths etc

- Limited GP registration – even though in the main literacy issues do not apply.
- Access to GPs and primary care impacted by being ‘below the radar’; mobile; enforced movement by CRT every 14-28 days.
- Serious concerns identified re inability of ambulance crews and health professionals to access boats in emergencies re GPS do not identify ‘bridge numbers’ although *“those guys are wonderful – they will climb over fences and across fields to get to you if they can and they need to but we can’t always get a [phone] signal and they can’t always get to us from the nearest bridge number”*

Boater – mid-30s, male articulate, Biological Science degrees x 2; (former medical journalist and freelance data analyst) fell on icy towpath – from bike.

Ambulance crew took him to hospital. Staff initially seemed reluctant to X-Ray doubting broken hip re age (in fact this is what had occurred).

On discharge back to boat after treatment, no care package/support, lack of awareness of the physicality of boat dwelling ie managing gang planks, limited movement with crutches in narrow boat etc. Reported stereotyping from staff re requests for analgesia [related to appearance/long hair etc.] and assumption that he had substance misuse issues when requested additional painkillers re limited access to GP and problems in returning for treatment given location of temporary mooring.

Subsequently developed an infection – reluctant to return to hospital re earlier treatment – self-medication administered until taken to hospital by friend.

Refugee and Migrant Women

- Findings drawn partially from FRA study 2011 http://fra.europa.eu/sites/default/files/inequalities-discrimination-healthcare_en.pdf (Greenfields as UK team member: http://bucks.ac.uk/research/research_institutes/idrics/idrics-projects/fundamental-rights-agency/) as well as on-going IARS (Comic Relief funded) project 2013-15. http://www.iars.org.uk/content/AbusedNoMore

- Significant body of evidence that vulnerable migrant and refugee communities are at particular risk of health exclusion – literacy and language issues, lack of cultural awareness of staff; poverty impacting on travel to surgeries, inability to register re lack of documentation, professionals' lack of awareness of mental health/PTSD issues; etc. http://www.fph.org.uk/uploads/bs_aslym_seeker_health.pdf
- Emergent evidence of decline in use of translators in some localities and assumptions that someone from a specific country would be aware of a particular dialect (even when they do not).
- Poor quality translation services or assumption that the client would bring a family member to assist cf: women who have experienced sexual violence being unable to disclose with male translator or family member present.
- A number of cases reported by interviewees of inter-ethnic tensions played out in care/translation settings.
- Cultural stigmatisation of victims of sexual violence; LGBT patients and people with learning disabilities

- 85 year old Sri Lankan lady, moved to UK as dependent relative of (working) children/grand-children. Limited English, grand-daughter translated when possible at appointments. Persistent eye problems, referred for surgery. Complication during surgery – patient did not understand what she was told on ward by staff, daughter/grand-daughter were unaware for 6 weeks (until post-op recall) that complications had accrued. Patient had remained in pain throughout this time, assuming that this was normal. Breakdown in communication with GP surgery compounded re missing letter explaining findings.

- 24 year old asylum seeking woman, gynaecological complications (following sexual violence in country of origin), initially unable to register with GP in London re lack of documentation, eventually registered using address of friend in another area of London. Problems with translation, referral, travel expenses to access medical appointment, wasted appointment re male GP (culturally unable to discuss health problems); lack of understanding of suspected health problem/referral/missing post re: not living at c/o address. Eventually hospitalised as an emergency re untreated infection/complications of infected FGM.

Similarities in Key Findings across all vulnerable groups

- Problems over registration – gatekeeping by front-line staff/receptionists
- Documentation/literacy issues
- Cultural misunderstandings
- Attendance for primary care when conditions often deteriorated considerably
- Lack of screening/difficulties engaging with the ‘system’ = late diagnosis
- Low levels of preventative screening/health literacy
- Stigma impacting on care/adverse stereotypes enacted by health care professionals
- Disrupted treatment regimes occasioned by frequent movement or non-compliance with medication (cf: external factors including lack of access to electricity etc)

Service Users' identification of barriers to care

- Getting through gatekeepers (GRT/B/R&AS)
- Lack of awareness of how system works/rights (G/T/R&AS)
- Short and inflexible appointments (G/T/B/R&AS)
- Lack of cultural competence/stereotyping/hostility (G/T/B/R&AS)
- Practical barriers – child care, distance travelled; lack of post, etc (G/T/B/R&AS)

Costs of Poor Quality Care

- Human cost (pain, suffering, avoidable mortality)
- Impact of diminished trust in services resulting from 'word of mouth' transmission of poor care experience
- Excess cost to the NHS resulting from late treatment of preventable condition (see further http://www.leedsgate.co.uk/wp-content/uploads/2013/06/Cost-Benefit-Analysis-report-Gypsy-and-Traveller-Health-Pathways.pdf) [estimated cost over 1 year – non-specialist health pathways > £20,000 per client]
- Impact on staff skills/trajectories/empathy

Staff Survey West of England (2013) – Key Barriers to Care

- Lack of appropriate ‘Read’ codes on IT system - frequently no identifying marker for Gypsies, Travellers, Roma, Boater
- Problem of ensuring continuity of care/referral to secondary care for mobile service users
- Literacy/language issues
- Cultural concerns/fixed health beliefs
- NFA – system set up for clients with formal fixed address (problems registering for care)
- Staff fear – health visitors/midwives going onto sites/towpaths, etc.
- Cultural Competence of staff

Good Practice Examples

- BANES – CCG commissioning follow-up outreach service to GRT/Boaters after 2013 report using specialist experienced staff. http://kanda.boatingcommunity.org.uk/%EF%BB%BFnew-welfare-service-provides-advice-and-support-for-liveaboard-boaters/
- Doncaster practice – use of health ambassadors from Gypsy communities; longer appointments; opportunistic screening/immunisations, hand-held medical records for nomadic travellers, flexible appointments: Immunisation levels 4% in 2003 to > 70% 2014. 2004, 0% cervical smear tests, 55%, 2014. http://www.gponline.com/gps-improve-healthcare-travellers/article/1325098

- Doctors of the World (health access and advocacy for vulnerable groups including vulnerable migrants, refugees/asylum seekers and homeless people) East London drop-in clinic http://doctorsoftheworld.org.uk/pages/london-clinic
- RAMFEL – one-stop shop for refugees, asylum seekers and vulnerable migrants (East London). Benefits advice, medical care and immigration support, food bank, etc. Special interest in supporing clients with mental health needs: http://www.ramfel.org.uk/wordpress/health-community-care/
- IARS "*Abused No More*" (see above) training sessions for health care staff on cultural sensitivity run by refugee and asylum seeking women based on the participatory action research undertaken in Phases 1-2 of the project. On-line training also available: http://www.iars.org.uk/content/online-training-gender#voices

Transferable and Comparable Good Practice Recommendations

- Embed cultural competence into training of staff pre and post-qualification (e.g. CPD points as incentives)
- Ensure Key staff with specific experiences/ competences are identified in within teams and across localities (community staff) + resource library
- Engage with CCGs/ in relation to joint commissioning – and across areas to save on resources
- Specialist outreach services/direct access by pt. and ‘one stop shops’ for vulnerable groups staffed by ‘experts’ with internships/rotations for other clinical staff.

QUESTIONS??

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