



## Including the Missing Voices of Disabled People in Gypsy, Roma and Traveller Communities

FINAL REPORT



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## **ACKNOWLEDGEMENTS**

The research team wish to thank all participants for their valuable contribution to this research project, which we hope has been constructive in opening up the debate about disability across Gypsy, Roma and Traveller communities.

## Executive Summary

All four nations of the UK have produced numerous policy documents in recent years, expressing the need for Gypsy, Roma and Traveller (GRT) communities to be treated more fairly and criticising the high levels of discrimination and oppression they routinely experience. These reports have had little effect and discrimination against GRT communities across the UK remains rife, despite the range of anti-discrimination legislation which offers protection in terms of race and disabilities.

The current project was designed in response to a funding call from the National Lottery Community Fund to identify the 'missing voices' of Disabled people. The voices of GRT Disabled people were identified as 'missing' by a project group led by the University of Worcester in partnership with Shaping Our Lives Service User and Disability Network, a user-led organisation.

The term 'GRT' encompasses a range of groups with different histories, cultures and beliefs although it is important not to aggregate the various cultures as if they were one and the same. Each community, even within close geographical proximity, can hold quite different perspectives. While specific issues addressed in policy documents include hate crime, accommodation, health and educational needs, there is virtually no mention of Disabled people's needs and their voices have not been heard within their communities. This project aimed to provide a platform for the narratives of Disabled people who live in GRT communities regarding experiences in accessing health and social care services. Their potential to join with Deaf and Disabled people's Organisations (DDPOs) and have their voices heard in key policy forums was also explored.

Surveys, interviews and focus groups were arranged via 'community connectors', within England, Wales, Scotland and Northern Ireland, this project being the first to explore issues of disability within GRT communities. Findings were that stigma and shame were often associated with a range of Disabled people in regard to their various sensory, cognitive and neurodiverse conditions, learning disabilities or physical impairments, mental health issues or long-term health conditions. These issues have not traditionally been openly discussed within many GRT

communities. Men, in particular, were less inclined to be open about issues of mental and physical disabilities, these being perceived culturally as weaknesses in many GRT communities. Across the UK, there is a cultural tendency to care for Disabled people within their own communities, with many being unaware of outside provision or DDPOs.

DDPOs took the general stance that they were inclusive organisations whose 'doors were open to all', but the reality was that only a tiny minority of GRT members were involved in such organisations and the voices of Disabled GRT members are not heard in policy debates. There was no general agreement across GRT communities about whether their Disabled members wished to combine with existing DDPOs. Focus groups took place in eleven communities across the UK, nine agreeing that they would use DDPOs, with two being of the opinion that the only services meeting their needs would be those run by their own members, previous experiences of joining outside groups having been discriminatory. Four accessible videos which illuminate the findings of this project are available as follows:

- Film 1 – 'The Missing Voices of Disabled Gypsies & Travellers'  
<https://vimeo.com/463393337>
- Film 2 – 'Missing Voices of Disabled Members of UK Roma Communities - Overview'  
<https://www.youtube.com/watch?v=UY5AMGtqRHU&feature=youtu.be>
- Film 3 - 'Our Doors are Open to All'  
[https://www.youtube.com/watch?v=IhWi\\_6YVEGg&feature=youtu.be](https://www.youtube.com/watch?v=IhWi_6YVEGg&feature=youtu.be)
- Film 4 – 'Missing Voices- Voices of Disabled Roma in UK'  
<https://www.youtube.com/watch?v=ZOtYaplatlY>

This project has started an open conversation about the position of Disabled people within GRT communities and we all have a responsibility to take this forward. Recommendations are that DDPOs should work together with GRT organisations in the interests of including all Disabled people. A charter to promote this way of working, particularly reaching out to the missing voices of men, is seen as a positive next step.

## Introduction

The project was made possible by DRILL (Disability Research on Independent Living and Learning), a five-year programme funded by The National Lottery Community Fund and led by Disabled people. The aims of this study were to build better evidence about approaches to enable Disabled people to achieve independent living, which is used to inform future policy and service provision, as well as give a greater voice to Disabled people in decisions which affect them. DRILL is managed by Disability Rights UK, Inclusion Scotland, Disability Wales and Disability Action Northern Ireland.

Current policy and literature regarding GRT cultures reflect that high levels of marginalisation and discrimination are widely experienced across the UK. However, report after report seems to have had little impact on changing these levels of oppression (e.g. Equality and Human Rights Commission, Scotland, 2013; Northern Ireland Human Rights Commission, 2018; Welsh Government, 2018; Cromarty, 2019; House of Commons Women and Equalities Committee, 2019). 'The last acceptable form of racism' (Traveller Movement, 2017) is a phrase which perhaps captures the ways in which the UK governments and the public at large behave toward GRT communities. This project is about disability within GRT communities, a topic not discussed in the many reports regarding housing, health, education and hate crime; indeed, the voice of Disabled people is absent from the policy and literature regarding UK's GRT communities. Furthermore, during the course of this project the government in England and Wales, proposed that overnight stopping should be criminalised (Home Office, 2019) despite opposition from the police. The net result of such oppressive policies is to eliminate, rather than integrate, the cultures of Gypsy and Traveller communities, whose traditional work in manual trades and crafts is also rapidly disappearing in a technological world. If you are Disabled and a member of a GRT community, the likelihood is that you will encounter intersectional forms of discrimination. Cromarty (2019) delivered a House of Commons briefing paper which highlighted such discrimination, stating that Gypsies and Travellers have the lowest rate of economic activity of any ethnic group (47%, compared with 63 % overall across England and Wales). The main reason for Gypsy or Irish Travellers being economically inactive was cited as looking after the home or family (27%, compared with 11% for England and Wales overall). The second

main reason for economic inactivity was attributed to being long-term sick or Disabled; at 26% this figure represented the highest proportion across all ethnic groups

## Purpose of the Study

The core purpose of this project was to give voice to the Disabled people who live in GRT communities, and to explore whether this voice could be heard in key policy forums, including having a presence in Deaf and Disabled Peoples' Organisations (DDPOs).

## Research Questions

The main research question asked why the voices of Disabled GRT members were missing and whether there was any potential for the concerns of these communities to be heard in service and policy arenas.

## Methodology

The project was a joint one between the University of Worcester and Shaping Our Lives Service User and Disability Network. Approval was gained from the University of Worcester Health and Sciences Research Ethics Committee, after which a steering group was established which consisted of GRT community members, academics and Disabled people. This group met every two months to discuss progress and emergent findings.

A mixed methods approach was adopted, including focus groups and online surveys for DDPOs (n.160) and GRT communities, additional hard-copy questionnaires being provided where required. The 'Missing Voices' project access was through a network of individuals who were from, or accepted by, GRT communities. We termed these individuals 'community connectors', many of whom worked for voluntary sector GRT organisations. It may be that openness to inclusion opportunities is dependent on ways in which such communities are approached, the community connectors' local knowledge being very helpful in gaining access to local communities, both as regards prior explanation of the project and through organising appropriate timings and venues.

Interest and willingness to participate in the project was initially difficult to attract, some GRT organisations having more pressing priorities and others feeling ‘researched-out’ and asking what this research would do for their communities. Eventually, with persistent networking and through contacts in GRT organisations and attendance at conferences and events, the project team were able to access eleven GRT communities across England, Wales, Scotland and Northern Ireland, three of which were Roma communities. Across these communities, a total of 106 members, many of whom were Disabled or carers of Disabled adults / children, attended focus groups, for which vouchers were made available. Press releases and articles carried by the University of Worcester / Travellers Times / Shaping Our Lives / Romani Cultural and Arts Company and others, all helped market the project. Flyers were sent out electronically and handed out at events and conferences. Community connectors were crucial players in translating the research information into Romanian, Romanes, and a dialect of Slovak Romanes, and they also helped establish working relationships with the researchers by explaining issues of confidentiality, consent and dissemination.

Focus group discourses were audio-recorded and transcribed. Overarching themes running through the narratives were then identified and documented. by way of thematic analysis (Braun and Clarke, 2006). Community members from the focus groups suggested that making films of their discussions would be acceptable to them and a good way to communicate positively about disability. Accordingly, two filmmakers from within GRT communities – Rosa Cisneros (Rosa SenCis Film Productions) and Lisa Smith (Rural Media) were commissioned to carry out this sensitive work. At all stages, assurances of confidentiality and anonymity were given to film and focus group interviewees, examples of which can be seen at Appendices 3 and 4.

Rural Media produced Film no. 1 below and Rosa SenCis Film Productions Films 2-4:

- Film 1 – ‘The Missing Voices of Disabled Gypsies & Travellers’  
<https://vimeo.com/463393337>
- Film 2 – ‘Missing Voices of Disabled Members of UK Roma Communities- Overview’  
<https://www.youtube.com/watch?v=UY5AMGtgRHU&feature=youtu.be>

- Film 3 - 'Our Doors are Open to All'  
[https://www.youtube.com/watch?v=lhWi\\_6YVEGg&feature=youtu.be](https://www.youtube.com/watch?v=lhWi_6YVEGg&feature=youtu.be)
- Film 4 – 'Missing Voices- Voices of Disabled Roma in UK'  
<https://www.youtube.com/watch?v=ZOtYaplatlY>

## Literature Review

The purpose of this review was to explore the specific topic of disability within GRT communities. The difficulty in finding relevant articles to fulfil this aim forced a change of tack, throwing the net more broadly across the landscape of relevant issues within these communities and focusing on more general health-related concerns. Within this broader context, disability, although rarely mentioned in the literature, can be considered a silent but significant factor.

There are estimated to be 300,000 Romany Gypsies and Travellers living in the UK. These communities are not homogenous but share certain commonalities as some of the most vulnerable and marginalised ethnic groups in British society. They experience multiple and acute forms of social exclusion (Ryder, 2014) which result in poor access to education, bad health, early mortality, and unequal access to services (Equality and Human Rights Commission (EHRC), 2016). GRT communities have been reported as having the poorest health of any ethnic minority group in Britain and worldwide (Van Cleemput, 2018; Condon et al., 2019), evidence of their health status largely being taken from their own perceptions of health, rather than from epidemiological studies. These groups often distrust officialdom, have high levels of illiteracy, and underutilise health care, thus limiting the possibilities of collecting objective data (Smith and Ruston, 2013). Being less likely to access health services than the general population results in a lack of statistical information about the prevalence and perceptions of various forms of disability within these communities in the UK.

Low levels of self-esteem, augmented by perceived discrimination by authorities and professionals seem to be key determinants to poor health status. Smith and Ruston (2013) conducted interviews with 39 Gypsies and Travellers (20 women and 19 men) aged between 18 and 66 living in South-East England, of whom 14 were living in conventional housing, 11

on council sites, three on private sites and 11 on the roadside. They found that all respondents were aware of and subject to discrimination on various levels (housing, law/crime, health support, education) which they believed to be due to their ethnic status. Indeed, the title of the article by Smith and Ruston, reflects the general feeling of the population featured in the study: 'If you feel that nobody wants you, you'll withdraw into your own...' (Smith and Ruston, 2013).

Exploring cultural differences, Rogers and Greenfields (2017) conducted a review of the small amount of data they could find on premature death and grief behaviours among British Gypsy and Traveller populations. They found that, within Gypsy and Traveller communities, there exists a cultural practice of not discussing death and a predominant need to 'protect' family at any cost, particularly amongst women who consistently put the care and protection of other family members above their own health and wellbeing (Rogers and Greenfields, 2017). They also highlight the existence of cultural taboos with regard to matters of mental health - '...those interviewed felt unable to seek help within the community suggesting that the extended family structure can both be an advantage and disadvantage – supporting an individual at times of need yet hindering engagement with mental health services.' (Rogers and Greenfields, 2017, p. 100). Male voices are still largely missing from debates on mental health and disabilities, despite a growing body of evidence about suicide risk. Parry et al. (2007) found that members of Gypsy and Traveller communities in England were nearly three times more likely to be anxious than the general population, and just over twice as likely to be depressed, with women twice as likely as men to experience mental health problems. The All Ireland Traveller Health Study (2010) found suicide to be the cause of 11% of all deaths in the Irish Traveller community. A recent study across England by Friends Families and Travellers (Sweeney and Dolling, 2020) found only 5 of 79 local suicide prevention plans mentioned Gypsy and Traveller communities, despite estimates that suicides in these communities are 6-7 times more common than in the general population. Initiatives such as 'One Call Away' a GRT - run 24/7 confidential phone line for men with suicidal ideation are very rare within GRT communities, but perhaps represent the beginning of a more open culture regarding mental health issues.

It is difficult to accurately assess the full extent of mental health issues experienced by Gypsies and Travellers, a problem which is significantly exacerbated by the lack of ethnic monitoring of Gypsies and Travellers within categories of service users accessing health and social care services. Even when relevant categories are included, a further obstacle to accuracy is that some community members will hide their ethnic status as a self-protective move against possible discrimination from service providers (Van Cleemput, 2010). Such beliefs are not without foundation. Health services, which have little contact, and therefore limited knowledge and poor understanding of GRT communities, will tend to have apprehensive and negative views towards this population (Heaslip et al., 2019). It is through mutual contact and respect that this fear of ‘the other’ can be challenged and changed.

The reluctance to approach health and disability services can be partially attributed to the stoicism of people within many GRT communities. Van Cleemput et al. (2007) interviewed 27 Gypsies and Travellers who had experienced ill health and found that:

‘...own poor health and of extended family members was normalised and accepted. Four main themes emerged relating to health beliefs and the effect of lifestyle on health for these respondents: the travelling way; low expectations of health; self-reliance and staying in control; fatalism and fear of death. Among Gypsies and Travellers, clear cultural beliefs and attitudes underpin health-related behaviour, and health experiences must be understood in this context. In this group, ill health is seen as normal, an inevitable consequence of adverse social experiences, and is stoically and fatalistically accepted.’ (Van Cleemput et al. 2007, p. 205).

Disability is not explicitly referred to in the above quote, but long-term ill health will inevitably involve some element of disability, hence it may be that similar attitudes exist within Gypsy and Traveller communities towards disability. The family unit is of crucial importance in GRT culture with much emphasis on caring for and protecting young and old members within the community. There is an expectation that members of a family support each other without resorting to mainstream community assistance and it is rare, for example, that Gypsy Traveller elders are placed in care homes. Gypsy Traveller men take

pride in a work ethic and providing for their family, Van Cleemput (2018, p. 682) noting that 'Time off to see a doctor or for ill-health is rarely considered unless seriously interfering with daily living.' Van Cleemput (2007, p. 111) had previously highlighted the impact of accommodation on health and the overall negative impacts of a travelling lifestyle, stating that while it might seem of benefit to move into housing for easier access to support and services, 'the psychological impact of giving up a travelling lifestyle and the potential 'culture shock' can counteract this perceived benefit.'

Life expectancy among the UK's Gypsy Traveller communities is estimated to be significantly lower than the wider UK population by between 10 and 12 years (Rogers and Greenfields, 2017). In the 2011 census Gypsies and Irish Travellers were included as ethnic groups for the first time, and data showed that only 6% were aged 65 years and over (Office for National Statistics (ONS), 2011). An overview of the general UK population in 2017 showed that 18% were 65 years and over. With shorter life expectancy, it could be hypothesised that some of the disabilities of old age are not as statistically prevalent in Gypsy Traveller communities as they are in mainstream populations, where life expectancy has largely been increasing in recent decades. Current UK Roma communities may also not experience a high incidence of old-age related disability as their UK populations largely consist of younger working age adults, whose elders may have remained in their countries of origin.

The history of discrimination and perceived social policies of assimilation (rather than integration) has made it difficult to engage with Gypsy, Roma, and Traveller communities for research purposes, especially in regard to taboo topics, such as disability. Condon et al. (2019) emphasised the challenges faced when aiming to conduct research with 'hard to reach' groups, defined as socioeconomically disadvantaged, socially excluded and seen as 'hidden populations' consisting of those who do not want to be identified (Bonevski et al., 2014). Lack of trust, fear of harm and ingrained cultural beliefs especially relating to sensitive health-related matters are considered key barriers to recruiting GRT populations for research (Condon et al., 2019).

Furthermore, any outside research or policy initiatives which might encourage greater inclusion also run up against the argument that what establishment organisations, including

universities, are really seeking is assimilation. This argument is particularly pertinent given current governmental oppression of GRT communities, Ryder (2014, p.22) having posed the key question 'can community development empower or does it present a new form of 'civilizing' project?' In Van Cleemput's (2007) study, the idea of integration through housing and education was seen as a threat to both culture and identity. As Powell (2011) pointed out, this fight to keep traditional cultural values and lifestyle is seen negatively by the welfare profession, with 'discourse being constructed around empowering notions of individualization and social integration; social processes that appear to be resisted or rejected by Gypsy-Traveller society' (Powell, 2011, p.489)

Breaking down the barriers that have hindered progress towards equality and inclusion and have remained in place for decades, is not simple, but while there is little effort there will be little gain. Fruitful communication is necessary if we are to find ways to understand and embrace cultural differences. Literature and policy are essentially silent on issues of disability within UK GRT communities and the voices of their Disabled members are absent, the 'Missing Voices' research project being designed to fill this knowledge gap.

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## Findings from GRT Communities Survey

### ***Where would you go to get help?***

**English Gypsy:** 4 females chose 'Family member' only

4 females chose 'your GP' and 1 also hospital and A&E

1 female chose both family member and GP

6 females chose variety of options – including family and mainstream services

The only male in the group did not give any option

***Was/is getting help easy?*** 3 respondents said yes:

### ***If it was easy, why?***

- Backing from a spinal unit
- Family are first port of call
- Accepted as a real person with needs.no discrimination at all.
- Very interested in the gypsy way of life, are my doctors

***The respondents that said it was difficult getting help - comments on the reasons why:***

- Information is too complex
- No help
- Just don't listen
- Views not understood
- Because folk don't often want to listen, especially authorities, they think problem solved when moving us on instead of helping us find a site
- Probably because I can't express myself fully
- Doctors mistrust you and they don't believe you and think you're a drug addict or just want to play the system
- No one listens
- Too many forms and appointments, waiting time long
- Difficult to get appointments and meet thresholds for services
- Being taken serious

Six respondents sought help from a charity for Disabled people. Of these, 2 sought advice about health problem; 2 about benefits; 3 to get equipment to help with a disability e.g. a ramp to help to get up steps.

One respondent sought help from social services

One respondent sought help about housing

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***Where would you go to get help?***

**Irish Traveller:** 2 respondents (1 male/1 female) chose 'Family member' only

1 female chose 'Irish centre'

1 female chose 'A local Traveller organisation'

1 male/1 female chose: Family member; Your GP; Hospital/A&E

1 male chose 'GP'

1 female chose: Family member; A trusted person in your community; Your GP; Hospital/A&E

1 female chose Family member; Local council services (like Traveller liaison Officer)

***Was/is getting help easy?***

Two said yes; because:

- I live in a supported living house
- Supportive family who understand issues faced by travellers

Seven said no. Reasons for the difficulties below:

- Council took four years to adapt flat

- Hard to communicate with people to get them to understand my problem
- Lack of support to help breakdown trust barriers
- No one wants to help Travellers
- Long process of assessments and multiple doctors
- No fixed address, not taken serious enough thought it was 'our' fault because of lifestyle
- Bureaucracy

***Have you tried to get help from a charity for Disabled people?***

Two respondents (1 male /1 female) said yes:

- To get equipment to help e.g. a ramp to help to get up steps; Advice about the health problem or disability
  - Advice about the health problem or disability.
- 

***Where would you go to get help?***

**Roma:** 1 male chose: Family member; Local council services (like Traveller Liaison Officer)  
1 female chose: Family member; A trusted person in your community; Your GP

The male respondent also commented: 'fitness or independent living adaptive martial arts or educational centre. Health or social services are last resorts - I try to focus on purpose and community resources.'

Both respondents said that it was not easy to get help.

The difficulties were:

Male: 'we are shamed in this region.'

Female: 'symptoms not taken seriously, multiple referrals with no help or diagnosis'

***Have you tried to get help from a charity for Disabled people?***

Two respondents said 'yes' and gave their reasons:

- To meet other people with similar long-term health problems or disabilities
- To get equipment to help e.g. a ramp to help to get up steps; Advice about benefits; Meet other people with similar long-term health problems or disabilities

The male respondent also sought 'other' help:

'Self-advocacy for Asperger's and support groups'

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**Where would you go to get help?**

**Scottish Gypsy Travellers:** 1 female: Family member; A local Traveller organisation; Your GP  
 1 female (43): Family member; Your GP; Hospital/A&E  
 1 male (25): Other – ‘our healer’

**Was/is getting help easy?** All respondents: no

**If it was difficult, why? –**

- Doctors don't care to listen or help
- Soon as you say Traveller/Gypsy it's an instant black mark against me. I was suicidal walking down the middle of the train tracks - the mental health hospital in my town said there was nothing at all wrong with me.

None of the respondents tried to get help from a charity for Disabled people.

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**Where would you go to get help?**

**Welsh Gypsy:** 1 female – GP and Local Outreach Services for Homeless People.

Getting help was not easy because there is no local Traveller Organisation.

Did not try to get help from charity for Disabled people.

**Findings from the Online Survey- DDPOs**

The online survey was distributed by Shaping Our Lives to approximately 160 DDPOs, receiving 20 replies across the UK, this 1:8 ratio suggesting that the topic of disability in GRT communities was not high on the agenda.

**1. DDPO Survey Responses:**

Online link sent to approx. 160 organisations  
 England: 9 responses  
 Wales: 5 responses  
 Northern Ireland: 1 response  
 Scotland: 5 responses

**Q: Does your DDPO have Disabled members from the GRT Communities?**

Country	Yes	No	Don't know
England	3	5	1
Wales	1	3	2

Northern Ireland	0	0	1
Scotland	0	2	3

Q: What type of services do you provide that GRT Disabled members can use?

All nations that answered gave the following options:

- Advice about rights for Disabled people
- Advice and guidance about benefits
- Advice and guidance about services
- Advocacy or support
- Personal budget and direct payments administration
- Training in using access equipment
- Social and leisure activities
- Volunteers

*Other:* Campaigning opportunities; Peer support; Work support; Assistance with assessments for health/social care, Access to Work; etc. / domestic abuse casework

Q: Are there any Disabled people from the GRT communities using your services:

Country	Yes	No	Don't know
England	2	3	2
Wales	1	3	1
Northern Ireland	0	0	1
Scotland	0	1	4

If no – do you know why?

- May not have declared (Scotland)
- None resident in our urban area (England)
- This is not an area we would generally record information on. We do not ask people to disclose gender, sexuality, race, religion, etc. unless required to do so by a particular project or if it is relevant to us providing a service. (England)
- We have never specifically targeted our recruitment at this group (England)
- Possibly because we don't target this group (Wales)
- We've never been approached (Wales)

Q. Do you provide any services only for Disabled people from GRT Communities?

All others answered 'no' plus one commenting 'Not needed, our services work for Disabled people from all communities'

- We do not have the capacity for specialist/bespoke services

- We have never been made aware that Disabled people from the Gypsy, Roma and Traveller communities need specialist/bespoke services (Scotland).

Q. Have you ever met with people (or their representatives) from the GRT Communities to discuss how your organisation could meet their needs?

Country	Yes	No	Not sure	If yes - when?
England	3	5	1	2: last 3 years; 1: last 12 months
Wales	0	5	0	
Northern Ireland	0	1	0	
Scotland	0	4	1	

One of the organisations that chose 'Other' (Scotland):

Not specifically met but involved in intersectional work that supports joint approaches.

There is awareness and relationships to build on. We are preoccupied with survival at the moment and specific developments suffer from funding cuts: we have lost development capacity.

Are there any barriers to working with the GRT communities?

Country	Yes	No	Don't know
England	5	2	2
Wales	0	3	2
Northern Ireland	0	1	0
Scotland	3	0	2

If 'Yes' please comment:

England:

- Current capacity;
- I think the people in these groups tend to keep to themselves
- It is difficult to make contact with our local community
- They are always scared to ask for help. Financially struggling
- Services are often not accessible to service users from GRT communities. Service users from GRT communities may have a distrust of services linked to discrimination experienced from statutory and community services.

Scotland:

- Capacity requirements - We have just one employee to cover the whole of region
- I think we would benefit from awareness training and some development support
- Capacity within team of development workers.

### **Other comments:**

#### England:

- In terms of our specialised services for Direct Payments and Personal Health Budgets, these rely on us receiving referrals from Health or the Local Authority. To our knowledge, we have never received a referral from a member of the particular group (GRT) or had a request from LA/Health staff for advice on this area.
- Our services are provided remotely on a national basis, so are accessible to all Disabled people and people with long term health conditions.
- I work for a specialist service for GRT communities. Discrimination against GRT communities is widespread across statutory and community services, and there is a lack of awareness about GRT communities - their cultures, and needs. Representation from GRT communities at policy level is important for change.

#### Wales:

- We would be happy to provide services if requested.

#### Northern Ireland:

- I think that people have negative attitudes towards people from the Gypsy, Roma and Traveller communities and it doesn't matter if they have disability or not.

#### Scotland:

- We treat all people equally and welcome enquiries from anyone.
- Happy to follow up.

In summary, the above small numbers of survey responses indicated that even the DDPOs who were interested in GRT issues had low levels of knowledge and contact, an 'our doors are open to all / we do not discriminate' type of approach being evident. A more pro-active stance than this is going to be needed if Disabled GRT members are to be encouraged to have a practice / policy voice in DDPOs. It was encouraging to see acknowledgement that DDPOs have much to learn about GRT and that some interest was expressed in reaching out to GRT communities. The point made about not collecting data on ethnic backgrounds is interesting but unless there are some measures of GRT usage, then the nature and extent of Disabled people's issues in such communities will never be quantified, making it easy for disinterested politicians or professionals to continue to marginalise such needs and lived experiences.

### Findings from Focus Groups and Interviews

Access to focus groups were facilitated by local community connectors and vouchers for attendance were offered to encourage take-up. Eleven focus groups were held in a variety of settings on sites or in GRT organisations' premises across the UK. GRT attendees (n.106) were predominantly female (n.96).

The focus groups were audio recorded and transcribed, using thematic analysis ( Braun and Clarke, 2006). The narratives were then analysed, drawing out the core themes of stigma; misconceptions about communities' caring capacities, difficulties in accessing services, attitudes to accessing mainstream services and suggestions for improvements in the field of disabilities and GRT communities. No special terminology seemed to be in common use to describe disabilities, there being a general agreement that disability was a private, and sometimes shameful thing to talk about even within families.

The brief of the project included exploring attitudes and experiences of mental health as well as physical disability but, as with other communities, most of the discussion centred around physical disabilities, despite mental health (particularly for male members of some GRT communities) being a serious, and growing, problem.

The focus groups held across the UK were concerned that support for site-based Disabled and non-Disabled people was inadequate and worse than the support provided to the

settled community. Extensive delays were reported in accessing steps, ramps, special mattresses, health care (e.g. toe-nail cutting), care for elderly people and child health monitoring, receiving mail and medication supplies. Comments about not being able to get post delivered and the attitudes of local services to visiting certain sites in particular meant a two-tier discriminatory level of service provision being present. It was generally agreed by focus groups that everyday living was more arduous if living on a site, especially for Disabled people and their carers.

No two communities visited held the same views about disability, but there was enough agreement to be able to identify common themes, notwithstanding that each local community had its own history and particular culture. Overall, a lack of knowledge about the Equality Act 2010 (only one community was aware of its existence and provisions) and a history of discriminatory services in general were shared across the GRT communities, Roma communities tending to express more positive views about attitudes and service accessibility in the UK when compared to their countries of origin. It is noteworthy that Roma attendees all lived in houses, rather than on sites, and generally experienced better services as well as having expressed greater trust in UK health and social care authorities. The sections below illuminate these above issues and provide further direct quotes from lived experience.

### **Lack of knowledge**

This research project is believed to be the first to explore issues of disability within GRT communities and it was apparent that this lack of everyday discussion among members meant that knowledge of disability, and rights under the Equality Act and service availability was very limited. The community connectors had some knowledge which they were able to pass on but their roles were very wide and often crisis-focused which meant they did not have extensive knowledge regarding disabilities. Apart from some very helpful leaflets on topics such as 'Your Right to a GP', there were no leaflets or other literature discovered during the research relating to disabilities.

The language barrier was an extra issue for Roma people:

First barrier would be language, I think, and second would be lack of knowledge of the existence of such services. They don't really know that they exist. (Roma)

The Roma Disabled people from our community, do not know their right and don't know where and what to do to access them.' (Roma)

For example, at the doctor we don't understand exactly the meaning, the terms, they are not able to provide Roma interpreter, therefore confusion and stress is caused.' (Roma)

I had a Disabled brother, right... he couldn't do nothing for himself. He was peg fed, machine for all his medication. We didn't know that we could get stuff off the NHS for him, because we were going out buying everything ourselves. We didn't know that we had to get stuff, we could get stuff off the NHS, because nobody told us. We bought his bed, we bought his nebuliser, everything. (Welsh Gypsy)

When asked where the community might go to seek advice on disabilities, answers ranged from family and own community (Roma), with trust being a key factor in any seeking of advice:

I would go to the local community centre, as there is a Roma staff and they offer support [with] completing some of the disability forms. (Roma)

I am going to Roma people from the community that I trust and I know that they have good knowledge about disability. (Roma)

### **Shame and Stigma**

Historical perspectives of shame and stigma perpetuated in some communities, although some evidence emerged that things were changing, especially with younger generations:

Nobody talks about their disabilities. It's shameful; we don't do that sort of thing because your business is your business isn't it? (Welsh Gypsy)

I think it's fear, because of being discriminated against in the past. I mean Gypsy Travellers have moved on a lot from years ago from the way they used to be, but the older generation are still there and I think it's fear because of being discriminated against so much in the past. (Scottish Gypsy Traveller)

Some people, like the elders think being Disabled or have Down's syndrome in their family is like a curse, or it depends on the religion. Some people see it in a different religion as a curse, or as a sin. (Roma)

Back in the days it was like a big thing to have like a Disabled person in the community, it was a really big shame. But now it comes more often we see, we have kids, and we're trying to be more welcoming and understanding. (Roma via Translator)

In the GRT communities visited as part of this project, there were no particular forms of language used in respect of Disabled people, most participants using words such as 'Disabled' or 'has a disability':

...in our community we all think the same, disability means 'disability' it's a 'handicap', it's related to your mobility and capacity (Roma)

'Special needs' is the nicest way of calling someone living with a disability. (English Gypsy)

We might say 'he's badly' or 'sick' (Scottish Gypsy Traveller).

The denial of disability onset was reported in a Scottish Gypsy Traveller group, partly because of the fear of what disability might mean to a family, in economic terms:

They don't like to say they are Disabled and they pretend they're not. Most see it as a sign of weakness.

In my family, they don't want to hear 'I'm not fit for work'  
You can't afford to be Disabled!

The particular reluctance of men not to acknowledge or seek help for a disability is perhaps related both to stigma and the economic consequences of not being able to work. General opinion was that men will not seek help with disabilities, again with some indication things might be changing:

I think there is still a very traditional way of living. Men usually go to work to support the family and women will stay home with the children...men will seek help from health professionals only if they really need to. (Roma)

You wouldn't tell people what was wrong, you would go into denial. You don't want to be judged, you don't want people to look at you or talk about you differently. Especially men wouldn't want to talk about it. (English Gypsy)

Too many of them kill themselves...they are taking their lives, they really are. Men in particular.... Men don't talk, they're too macho, well maybe they're macho (Welsh Gypsy)

A more hopeful view was expressed in a Northern Ireland focus group:

A lot of men now do go to the doctors. Because years ago no, a man would never go to a doctor. And I'd never go to a doctor myself unless I would be sick. But men do go now over this prostate cancer and all this stuff. A lot of them do, even younger ones do. (Irish Traveller)

### **Presumptions made about the caring capacities of GRT communities**

There was a general consensus across all focus groups that GRT families do 'care for their own' where they can. This is summed up in the following quote:

...when it comes to physical disabilities within the Gypsy Traveller community there's a very caring culture...there's a lot of kind of shared caring. People share it within families but also if you live on a site, a lot of people in the site will do what they can to help people who have a physical disability. I think when it comes to mental health issues, I think it's slightly different if people are maybe a bit more reluctant to talk about that. It's much more hidden. (Community Connector, Scotland)

A Scottish Gypsy Traveller focus group also thought that the 'authorities' had a 'one size fits all' view of GRT communities, using the phrase 'middle people':

...they don't think we've got children, they don't think we care for people with dementia. They don't think we've got Disabled members. They just see us as Gypsies. They think we're all 'middle people', all the same.

The caring nature of families within GRT communities was believed by some groups to be an excuse for non-provision of services. The starkest example here came from a Scottish Gypsy Traveller focus group:

... we had the caravans and we have the chalets, no washing machines or tumble dryers was allowed in the chalets, so there were out in the shed and there was no way of getting up into the shed for a wheelchair. So I applied for someone, for the council to put a ramp in and they refused. So the OT sent me a letter saying - the occupational therapist - she sent me a letter stating that because I was a traveller

and I had a husband and travellers were very family orientated, that she didn't have to put one in. So they never bothered for years.

Stoicism and a distrust of 'the authorities' are also reasons why GRT communities prefer to care for their own where possible:

There's people here who will help you out, you would never need to call an ambulance, I'll drive you, you drive me. We'll feed each other's children or get each other's shopping. If you need help, we'll drop what we're doing and help. (English Gypsy}

If one family has a crisis, the family's all there for them, they help out each other. And if it's a disability we would help a little bit more in help as well with the disability, families that has disability, because we don't get much information, like we have to look for it our self (Irish Traveller)

It's very rare in a travelling community that an older person has to go into a home.' (English Gypsy)

One scenario encountered by the research team involved an older man who was cared for by his family on a small site, despite very cramped conditions and a lack of Disabled facilities meaning that the care sometimes had to be carried out in a rather undignified way. The family were adamant that they would never allow their relative to go into a home or house with support but when the man was asked by the researcher why he had never considered a house or attending a Disabled persons' group, he replied that he had never been asked, and that he would like to try those options. This was a 'one-off' case but it does pose the question of whether the caring culture, or perhaps a tendency to 'over-protect', is always in the best interest of individual Disabled people. The historical examples of not being welcome or being discriminated against by non-GRT organisations make such stances understandable, and there is clearly an onus on all disability-related services to reach out to GRT communities. Survey replies from DDPOs which state that their doors are 'open to all' are not enough to encourage Disabled GRT members to attend their groups. Additionally, the stigma around disability also suggests that Disabled people are not keen on joining groups, but would rather attend one-to-one type services.

## Houses or Sites – Differential Services

Use of Disabled services and organisations by GRT members seemed sparse overall across the UK, with the issues of lack of knowledge, stigma and a presumption of familial care all contributing to this reality. Further complications for Disabled GRT people arise depending on whether they live on sites, travel regularly or live in houses. One particularly stark example was given by an English Gypsy whereby moving to a house address brought about access to a GP and other health-related services ‘overnight’. Successive social policies of governments across the UK have led to Gypsy and Travellers’ ways of life being curtailed, most notably the lack of provision of stop-over sites and the lack of investment in new sites, which could be designed for accessibility.

...the biggest issue is health services seeing that the only solution for Gypsy Travellers living on sites and in caravans is to move into settled accommodation and the only way their needs can be met is by being in mainstream housing and, you know, that seems to be the only solution. There doesn’t seem to be any sort of creative thinking around more culturally appropriate solutions. It seems to be just- ‘the only way we can work with you is if you move into settled accommodation’.  
(Community Connector, Scotland)

Roma, despite long histories of nomadism in their countries of origin, all live in houses in the UK as a preferred lifestyle, even if much of this is in poor private sector housing stock with little in the way of disability provision:

Unfortunately the houses that the Roma communities are living here are not properly equipped for any kind of disability, especially physical. So there isn’t any kind of, there’s lack of providers of housing, and most of them would go through private landlords, and they usually don’t really accommodate disability, no. (Roma)

The situation of Mary (not her real name) below, illustrates the oppressive nature of UK housing policies, and how culture is ignored by policy makers:

‘Wouldn’t your daughter’s needs be better met in a house?’ I said ‘I have no doubt about that, I said hundred percent, I do believe so yeah. But I said that’s not Mary’s way of life, that’s not my way of life. Mary’s a traveller’. I said ‘Why can’t her needs be met on a site where I have carers and everything round about me to help me?’ And I turned the table, I said to the man that was leading the board, I said ‘Could we turn it round a bit for a moment, what if I asked you to move from some nice house out there and, no doubt, posh cars’, I said no doubt, I said ‘What if I asked you to

move onto a site'? I said 'Leave your environment, move onto a site...because that's what you're trying to do to me'. (Scottish Gypsy Traveller)

One focus group recognised that new housing monies were not being spent on building or improving sites:

The monies from the government push for new housing has not been spent on investment in new sites, so there's millions of pounds of funding to build houses, but nothing for sites (Scottish Gypsy Traveller)

The majority of participants in the focus groups lived on sites, with a smaller number living in houses, the general view being that all services were more accessible with a house address, despite the loss of community that often accompanies a move to bricks and mortar:

I think people try to care in bricks but you can't be there 24/7. On a site you can be there 24/7. In a brick place you have family coming in and out but it's not the same. [On sites] You look out for each other. We know each other's habits and keep an eye on each other. We keep each other going and know if we're in trouble if we're not keeping up our habits. (English Gypsy)

Coping with disabilities on sites where toilet and shower facilities are usually situated in a separate block to the living areas can cause great distress for both carers and cared-for:

Toilet access can be a huge issue when living on a site. Access to showers can be a huge issue, there are not Disabled toilets on sites. (English Gypsy)

And sometimes there is no help like for with my mum who was wheelchair-bound and it was steps going into the chalet and it needed three of us to lift her and the wheelchair into the chalet. (Scottish Gypsy Traveller)

Additional site problems included that of Disabled people's needs to store certain medicines:

You may not have a fridge or you cannot have your generator on all the time to cool the medicine. If you're Disabled you may need extra items such as oxygen tanks but you may not be able to fit these into a caravan. (English Gypsy)

Furthermore, certain sites had become tarnished with a bad reputation which meant problems arose in getting services to visit Disabled or sick people:

You can't get carers to come into the site due to health and safety. (English Gypsy)

One of the problems is some sites an ambulance going onto a site needs a police escort. On unauthorised sites you won't be able to get a call out from a GP. It is a two-tier system! Personal health budgets which means you can employ families or people close to you. An older man from the community did not want a stranger to do his caring. You have to persuade NHS to do this. (English Gypsy)

### **Previous bad experiences of accessing support**

The majority of respondents reported numerous examples of previous poor access:

... they would give me some leaflets in English and would send me home, that's it. And they expect [me] to understand everything. (Roma)

The doctor tells you they're fully booked, they don't give you appointments. (English Gypsy)

One surgery said I'll take you on, but don't tell the others. (English Gypsy)

If a traveller...because she was down and out, she's kind of afraid to speak out because she's thinking of her children, she's thinking of her partner, she's thinking of her home, do you understand? She doesn't know how she's going to be looked at, if you understand me. (Irish Traveller)

You would go to A& E and hope for the best. You can't always go to a GP... they'll ask for your ID and some people don't have them. (English Gypsy)

But even in the GPs when you go, you don't see a flier about disabilities. (Roma)

### **Previous Positive Experiences of accessing support**

Upon being asked if they thought non-travellers and travellers received similar levels of support from health and social care professionals, several answers were positive:

Any doctor or nurses that I've ever seen with anything, they've been always very good. (English Gypsy)

They give you good advice don't they? That's one thing I can say about them. (Irish Traveller)

Some GPs suggest some places for you to get help and some places don't. We, as Roma, you know, we're very welcome people. Even though they have disabilities or they don't have disabilities. (Roma)

However, there was an acceptance that sometimes a family might have to travel a long distance to see a doctor known to be empathic to GRT communities, such a logistic meaning that preventive visits were unlikely to be commonplace. Historically, access to support services had often been far from equitable, as the following description of attitude from a doctor's receptionist illustrates:

Remember that time you wouldn't have to give your name, you'd just get in the queue, tell her your name and she used to let a load of people in front of me, and I got fed up with it. So I stood up and told her... I got up and complained to the doctor. The doctor came down and gave her a bit of abuse anyway. (Irish Traveller)

### **Willingness to join DDPOs or similar disability organisations**

All groups gave examples, historical and contemporary, about officialdom deterring service uptake either through indirect or direct discrimination, such experiences having affected views about whether they would consider joining mainstream DDPOs or similar disability organisations. However, some examples of positive receptions from medical and other settings were given to balance against the discriminatory ones such as where GPs would not accept GRT people onto their lists, or refused to send them for second opinions.

Two of the eleven focus groups thought that they would not approach DDPOs, especially as they have never been reached out to previously. However, most groups were more willing to see what such organisations might offer to Disabled GRT, even with some reservations. In Northern Ireland, mainstream services seemed well attended;

Yeah, I've been to a lot...I do go to them. (Irish Traveller)

I mix in with not only my own community; I mix a lot with the community..... I enjoy mixing in with other people... (Irish Traveller)

...Respect the other communities the same as you'd like them to respect you. (Irish Traveller).

English Gypsies seemed largely open to trying mainstream disability services, as exemplified by the following quotes which shows again the key role of community connectors:

Yes, we do have a good relationship with [name of organisation] who support young people with disabilities. We've got people linked in. We've built relationships so people will use those groups. (Community Connector, England)

We've got a great Doctor here, and if we have a problem, we go to [name of community connector] (English Gypsy)

Most Roma participants had also either accessed some kind of disability organisation or were prepared to do so, often comparing UK services far more favourably than those in their home countries:

On her son's part he will love to go to some place like that, because he likes to go some places like that. (Roma-via translator)

The Romas are quite friendly, in my experience they're quite sociable, and if given a chance they would, I believe so, yeah. (Roma)

Scottish Gypsy Travellers were more mixed in their opinions about whether they would welcome mainstream disability initiatives, or would only attend if 'run by our own'. Others reported already using a carers' centre and being really welcomed and accepted. Similarly, several Welsh Gypsies were able to report positive involvement in mainstream disability groups, both for adults and children.

### **How to improve matters for Disabled GRT community members**

All of the focus groups suggested positive ways in which discussion and understanding about disability matters, possibly leading to better services, might be attained. The Roma groups focused on language barriers and suggested that Roma interpreters should be made more readily available within disability services and organisations. Roma people were generally positive about using mainstream disability services. The potential of formats such as video were thought to be positive ways forward as was the use of social media. There was some support for forming a Roma disability network which might meet regularly have drop in sessions locally. The aim of such a network would be to promote the information related to disabilities, new projects, support with completing forms and accessing their rights under the Equality Act 2010. Roma communities also encouraged disability organisations to come to them:

Come to our events. When it's happening, something in the community, them to come to be visible ... to show them that this service is, that they have also priority to receive these services. Because we have this in our mind, because we have discrimination we're like persecuted in our past, we have this [lack of] self-confidence. (Roma)

Gypsy and Traveller groups had more hesitation than the Roma groups regarding embracing outside disability organisations, largely because of previous discriminatory practices, which have largely not been the contemporary experience of many UK Roma. The lack of general information about disability organisations was highlighted by Gypsy and Traveller groups,

Maybe if they advertised it [community services] more, maybe more like posters or something, things that maybe is going on like for Disabled people. At the doctors or... (Scottish Gypsy Traveller)

It should be advertised at your local area, there's this for disabilities, sports or whatever, because some poor people don't come out. (Irish Traveller)

The importance of reaching out early regarding mental health problems was emphasised, especially in relation to men, the need to get younger people to be more open being seen as important:

I think you have to start from young mental health like the teenagers. Because the older ones, they're like they're set in their ways. And it takes a lot for to get through to them. So I think what they'd have to do is start to the younger ones and let them talk about mental health more. (Scottish Gypsy Traveller)

## Summary of Overall Findings

This project was a year-long venture aiming to uncover why views of Disabled people from the GRT communities remain unheard and excluded from social policy debates. The 'intersectional discrimination' associated with being a member of a GRT community who is also Disabled, came through in many of the narratives across the UK and it was found that the vast majority of DDPOs had little knowledge or experience of the GRT communities in their localities. The potential mutual benefits in joining forces and using DDPOs to promote the Disabled voices within GRT communities were explored but no definitive way forward emerged. Some GRT communities were of the opinion that they would only attend such services if run by their own people, whereas the majority of community members who

participated in the research were open to trying such services, if only they were made aware of their existence in ways which welcomed them proactively. Overall findings are summarised below:

- Cultural legacies of shame and stigma regarding Disabled community members remained, with some evidence that such views were changing.
- Deaf and Disabled Peoples Organisations (DDPOs) do not reach out pro-actively to Disabled GRT people in their communities; a few say they have some GRT members but most say 'our doors are open to all', which does not facilitate inclusion.
- There was a low level of interest shown in the Missing Voices project by DDPOs, many of whom were struggling to survive in times of austerity.
- Many GRT families seem to care for their own, both by default of knowing about local services / organisations plus a fear of outside organisations being discriminatory.
- Some Disabled people in GRT communities may be sheltered in ways that mean they do not fully realise their potentials.
- There were mixed views across the nations about whether GRT communities would use 'mainstream' DDPOs as a way of having their missing voices heard. Two communities stated that they would only use disability services run by their own members, whereas the other nine communities were more open to ideas of integration. In one instance the views of one community differed starkly from those of a very similar community within the same geographical region, suggesting that local customised initiatives might be the way forward.
- The role of 'community connectors' (liaison -type staff employed by charities or government agencies who were sometimes from GRT communities) were seen by community members and the research team as critical links. In the main, however, the knowledge held by the community connectors about disability issues was patchy, and they held no specific guidance regarding Disabled organisations / services being accessed locally.
- The project represented the first opportunity to hear the hitherto missing voices of Disabled members of GRT communities and participants in the focus groups were appreciative of the debate having been brought into the open. The GRT community has seen a plethora of reports over the years cataloguing the discriminatory health and living

conditions of Gypsies and Travellers, yet little has changed. If anything, mainstream society is becoming more punitive towards Gypsy and Traveller lifestyle, as evidenced by the current government seeking to criminalise overnight stopping.

- Traditional occupations of travelling families have been rapidly disappearing in a digitalised and ever-regulated economy and many families have been 'forced' into settled housing accommodation as their nomadic lifestyle becomes marginalised. Conditions for Disabled people within housing may have better facilities than on the road but the loss of immediate community is believed to have led to greater incidence of loneliness and mental health, suicide rates among men being extremely high.
- There exists a culture in which GRT men do not acknowledge illness / disability as it is seen as a weakness. They do not talk about mental health, discussions during the project having almost exclusively focused on matters of physical disabilities. 90% of focus group attendees were women.
- Life expectancies of Gypsies and Travellers remain some 10-12 years lower than other UK residents.

### Meeting DRILL's Four Principles

**Knowledge** – This research project is believed to be the first to bring together knowledge about disability within a GRT context and will complement existing bodies of knowledge around other aspects of GRT cultures. This report, other planned articles and media exposure, together with the four films emanating from this project represent a significant contribution to a previously hidden area of knowledge.

**Policy** - Policy has ignored the specific consideration of disability in the many reports produced about health and wellbeing in GRT communities over the years. The evidence in this report that disability is still often shrouded in stigma and shame means that available services are not known about and therefore not used. There is a key policy message here for the outreach activities of health and social care organisations and for community connectors to become more informed about local availability of disability services and rights under the Equality Act 2010.

The British Association of Social Workers (BASW) have been particularly interested in this project and have acknowledged the lack of profile given to GRT issues across their profession, beginning with initial training. Consequently, a motion was passed at the September 2020 BASW AGM urging the organisation to push for GRT issues to rise up their national agenda. The project has also helped create an interest that has led to a first ever meeting of key social workers and academics to see how the GRT profile can be raised and a group of GRT background social workers is also being set up for the first time ever, partly to add needed knowledge, but also to act as role models for members of the GRT community who may aspire to professional careers such as social work.

Core research partner, Shaping Our Lives User Service User and Disabled Persons' Network has also entered new territory in this exploration of Disabled GRT issues and will ensure that future initiatives and campaigns are alive to GRT communities and intend to produce policy guidance for DDPOs in this regard.

**Wellbeing** – Members of every focus group mentioned how the open discussions had made them feel better about discussing a hitherto rather stigmatic topic. Some members subsequently agreed to be filmed talking about disability issues and it is hoped that these films will also help increase wellbeing among Disabled GRT members and carers who may be encouraged to explore local disability services. For DDPOs the message is that saying 'our doors are always open to all' is not good enough to attract local GRT members and it is hoped that those DDPOs will reach out in more focused ways to Disabled members of their local GRT communities.

**Empowerment** – This research was carried out in co-production with Disabled people and GRT community members. Members of the steering group have become empowered with new knowledge and insights and have been core to a successful research project from start to finish. GRT community members have been empowered to speak out about a previously taboo subject and some have come forward to be filmed talking about their experiences and aspirations, providing role models for others.

## Discussion

This project was believed to be the first to discuss issues of disability across a range of GRT communities, this topic having previously been largely taboo among GRT communities. The communities who volunteered to participate were pleased that this was a first step towards opening up this debate and were keen to learn about legal and policy provision across the UK that gave Disabled people certain rights. It was notable that almost all of the discussions with GRT groups were about physical, rather than mental, health and disabilities. This suggests that greater shame and stigma remain attached to mental health, despite the urgent concerns about suicide rates, especially among young men, being so high (Sweeney and Dolling, 2020)

Most communities placed great faith in the work of their community connectors, whose roles and responsibilities are extensive and whose knowledge of the detail of policy and law regarding Disabled people was found to be limited. They were largely unaware of the presence of any local DDPOs, whose numbers have declined in the face of austerity policies (Unison, 2013). Responding DDPOs (n.20) were largely unaware of the needs of GRT members within their localities, and despite having 'open door' policies, only four reported having any GRT members in their organisation. In discussing GRT communities it is very important to stress that they are not homogenous, indeed sometimes quite different views were held by groups in nearby localities, even when cultures were shared. The situation of Roma is quite different in many ways from that of indigenous Gypsy and Traveller groups in the UK. The Roma families share histories of structural persecution and oppression but largely see UK society as representing lower levels of discrimination than in their countries of origin, and believe the general standard of schooling, health and social care in the UK is often far superior. Most Roma are economic migrants, keen to become integrated with mainstream UK society and its employment opportunities. Families who have migrated to the UK tend to be younger than the average family profile of indigenous Gypsies and Travellers and hence the prevalence of disability is less. Some families reported having left their Disabled members back in their home countries where relatives looked after them, aided by monies sent back home. In general terms, the Roma participants in the study spoke positively about access and treatment within health and social care services. The

experiences of indigenous Gypsies and Travellers were far more mixed, with many examples of direct and indirect discrimination having been part of both their past and recent history.

The levels of knowledge about how best to engage with Disabled members of GRT communities was low across mainstream organisations, community connectors perhaps holding the key regarding access to services. However, inclusion initiatives in the field of disability cannot be the sole remit of community connectors, whose work is essentially generic and often crisis-driven. Health, social care and DDPOs must also be pro-active in reaching out to GRT communities – saying that ‘our doors are open to all’ will not lead to better services and quality of life for Disabled members of GRT communities. It is encouraging to see the steps currently being taken by BASW with regard to inviting GRT members to conferences, pushing for GRT education within social work training courses and the establishment of a GRT group within the social work profession.

From a rights perspective, some interesting dilemmas were encountered with regard to the culture of ‘caring for our own’ within GRT communities, possibly meaning some Disabled people are not having their full potential realised. One example concerned a Disabled older person, cared for very lovingly on a small site, but where the day to day effort in accessing toilet and washing facilities were very stressful and undignified. The person in question told the researchers that they would be interested in living in settled accommodation and would also like to try out day centre-type activities as they were very bored. However, the family were not open to these suggestions, fearing for their relative’s safety in the outside world and being committed to a travelling lifestyle. Other Disabled GRT community members did not generally access any mainstream disability services because there was no local knowledge of these services, such services had not reached out to GRT communities, or through fear, based on previous experiences of mainstream services being discriminatory and non-inclusive of GRT community members.

## Conclusion

Historical and present-day oppression of GRT communities continues across the UK, both at governmental and street levels, where Disabled GRT people encounter an extra layer of

discrimination. The present research project was innovative in that new ground was broken in opening up the discussion about disability within GRT communities, a discussion that now needs to be furthered within those communities and with outside health, housing and social care agencies.

Much has been written about health issues and life expectancies across GRT communities but within these communities, many of whom are stoic and private by culture, open discussion about mental and physical disabilities is uncommon and often taboo. Many focus group attendees commented how helpful they had found being able to bring such matters into the open without fear of judgement.

The four video films which accompany this report bring the above issues to light, these films having been instigated and shaped by the focus groups, whose wish was that they were created by film-makers from their own communities. Great care was taken to ensure that the films were as inclusive as possible, and they too break new ground in the exploration of inter and intra-generational disability issues within GRT communities.

The 'Missing Voices' project has started the disability conversation within GRT Communities and we all have a part to play in further developing this conversation into action.

## Recommendations

- DDPOs should work with d/Deaf and Disabled people from GRT communities by making culturally sensitive adjustments to services. Pro-active approaches, such as working with local GRT community connectors and leaders is seen as a fruitful way forward.
- GRT organisations should invest in training to extend their expertise into the fields of disability and ensure that their 'community connectors' are conversant with the Equality Act, 2010 and include local disability organisations in their networking.

- Shaping Our Lives Service User and Disability Network could facilitate DDPOs in reaching out to GRT communities, using the experience, relationships and trust gained during the present research project
- National DDPOs might create a charter for d/Deaf and Disabled people from GRT communities, aiming at transforming the voices of Disabled GRT communities from 'missing' to 'present and vocal'. Such a charter could attract media and political interest which could help ensure the particular experiences and needs of Disabled people within GRT communities are embraced alongside all others.
- Local authority social care organisations should be more proactive in their disabilities work with GRT communities, particularly in regard to preventive mental health interventions.

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Appendix 1: Example leaflet / poster



## Missing Voices of Disabled People in Gypsy, Roma & Traveller Communities



Our research team is made up of disabled people, members of the Gypsy, Roma and Traveller (GRT) community and academics.

We wish to:

- ⇒ find out if voices of disabled people who live in Gypsy, Roma and Traveller communities are being heard
- ⇒ explore whether these voices could be heard in key policy forums and have a presence in disabled people's organisations
- ⇒ identify barriers in accessing health and social care services



*'...the voices of older Gypsies and Travellers are very rarely heard – and 'they become an invisible population within a marginalised community' (EHRC Research Report 12, 2009).*

Some views of healthcare from people in the GRT community:

*'... I've done two or three hundred miles to keep a doctor because he's been reliable and he likes you and you like him.'*

*'Prejudice has a big impact on your physical health because you withdraw from society. So you won't go to the doctors and then you withdraw...'*

Please feel free to talk to us!  
Contact Peter Unwin  
p.unwin@worc.ac.uk



You can use the back of this leaflet to leave any comments or share your experiences.



## Appendix 2: Survey Questions for Deaf & Disabled Peoples Organisations

The University of Worcester and Shaping Our Lives (a user-led organisation for service users) are doing some research about Disabled Gypsy, Roma and Traveller people. We would be very grateful if you could answer a short survey below.

**1. Do you have Disabled members from the Gypsy, Roma and Traveller Communities?**

Yes/No/Do not know

If yes, do you know how many? Please provide any information below.

**2. Do you provide services for Disabled people from Gypsy, Roma and Traveller Communities?**

Yes/No/Do not know

**3. Do you provide services that can be used by Disabled people from Gypsy, Roma and Traveller Communities?**

Yes/No/Don't know

If yes, what type of services? (Please delete those that do not apply)

- Advice about rights for Disabled people
- Advice and guidance about benefits
- Advice and guidance about services
- Advocacy or support
- Social and leisure activities
- Volunteers
- Other, please comment

**4. Are there any Disabled people from the Gypsy, Roma and Traveller communities using your services?**

Yes/No/Don't know

If no, do you know why?

**5. Do you provide specialist/bespoke services for Disabled people from Gypsy, Roma and Traveller Communities?**

Yes/No/Don't know

**6. Do you provide any services that are only for Disabled people from Gypsy, Roma and Traveller Communities?**

Yes/No/Don't know

If no, please select all that apply:

- Not needed, our services work for Disabled people from all communities

- We do not have the capacity for specialist/bespoke services
- We have never been made aware that Disabled people from the Gypsy, Roma and Traveller communities need specialist/bespoke services

**7.** Have you ever met with people (or their representatives) from the Gypsy, Roma and Traveller Communities to discuss how your organisation could meet their needs?

Yes/No/Don't know

**8.** Are there any barriers to working with the Gypsy, Roma and Traveller communities?

Yes/No/Don't know

If yes, please comment

Please add any further comments that may be helpful to our research

## Appendix 3: Informed Consent Form



### INFORMED CONSENT FORM (NON-NHS RESEARCH)

**Title of Project**                      **Including Missing Voices**

**Participant identification number for this study:**

**Name of Researcher**    **Dr Peter Unwin**

I, the undersigned, confirm that (please initial boxes as appropriate):

1.	I have read and understood the information about the project, as provided in the Information Sheet dated _____ or it has been read to me.	
2.	I have been able to ask questions about the project and my participation and my questions have been answered to my satisfaction.	
3.	<p>I understand that taking part in this study involves the following:</p> <ul style="list-style-type: none"> <li>• You will be asked whether you wish to be part of a focus group or interviewed by telephone or in person.</li> <li>• All interviews in person will be carried out at a mutually convenient place and will be noted, removing any personal identifiers. Interviews will be approximately 20 minutes long.</li> <li>• All information, will be anonymised so that is not identifiable and you will be given a code number should you wish to withdraw your contribution at any time up until January 31st 2020. All information will be kept securely and kept for up to a maximum of 10 years after the project ends in March 2020, and then disposed of securely.</li> </ul>	
4.	I understand I can withdraw at any time before analysis of the data i.e. Before January 31 <sup>st</sup> 2020, without giving reasons and that I will not be penalised for withdrawing nor will I be questioned on why I have withdrawn.	
5.	<p>I understand that the information I provide will be used for:</p> <ul style="list-style-type: none"> <li>• research reports;</li> <li>• conference papers,</li> <li>• journal articles or other publications).</li> </ul> <p>Any information disseminated / published will be at a summary level and will be fully anonymised and there will be no way of identifying your individual personal information within the published results.</p> <p>The summary and conclusions arising from the research project for teaching and further research purposes. Any information used in this way will be at a summary level and will be fully anonymised. There will be no way of identifying your individual personal information from the summary information used in this way.</p>	
6.	I agree that my information can be quoted in research outputs	
7.	The procedures regarding confidentiality have been clearly explained (e.g. use of names, pseudonyms, anonymisation of data, etc.) to me.	
8.	I understand that personal information collected about me that can identify me, such as my name, or where I live, will not be shared beyond the study team.	
10.	I understand that other researchers will have access to this data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have	

	specified in this form.	
11.	I voluntarily agree to participate in the project.	
12.	I know who to contact if I have any concerns about this research	

.....  
Name of Participant

.....  
Signature

.....  
Date

.....  
Name of Researcher

.....  
Signature

.....  
Date

## Appendix 4: Participant Information Sheet



### **Participant Information Sheet –Disabled People’s Organisations or Gypsy Roma Traveller Focus Groups**

#### **Title of Project: Including Missing Voices**

#### ***Introduction***

We would like to thank you for your interest in the above research project. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this carefully and ask the research team (details below) if you have any questions. Talk to others about the study if you wish. You will have up to two weeks to decide if you want to take part before you will be contacted again.

#### **What is the purpose of the study?**

We see the core purpose as being to hear the voice of Disabled people who live in Gypsy Roma Traveller (GRT) communities, and to explore whether that voice could be heard in key policy forums, including having a presence in Deaf and Disabled People’s Organisations (DDPOs).

The results of this research may lead to the development of further research into the ways that people from GRT communities could be actively involved in shaping the future in regard to getting the voices of Disabled GRT people heard.

#### **Why have I been invited to take part?**

Your personal views or views will be very helpful in adding knowledge and insights to the core research.

#### **Do I have to take part?**

No. It is up to you to decide whether or not you want to take part in this study. Please take your time to decide; we will wait for up to two weeks before contacting you again. You can decide not to take part or to withdraw from the research without any consequence.

#### **What will happen to me if I agree to take part?**

If you agree to take part, you will be asked to take part in a group discussing your experiences of disability. All interviews will be audio-recorded and noted, removing any personal identifiers.

All information, will be anonymised so that is not identifiable and should you wish to withdraw your contribution at any time up until January 31st 2019, then just let Peter Unwin know - [p.unwin@worc.ac.uk](mailto:p.unwin@worc.ac.uk) . All information will be kept securely and kept for up to a maximum of 10 years after the project ends in March 2020, and then disposed of securely.

### **Are there any disadvantages or risks to taking part?**

The researchers have not identified any risks to taking part in this project. We do not envisage any extra support needs arising for you as a result of taking part in this research. However, if you wish to talk to somebody about any issues you may have, please contact the lead researcher

### **Will the information I give stay confidential?**

Everything you include in your responses will be confidential, unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. The information you give may be used for a research report, but it will not be possible to identify you from our research report or any other dissemination activities.

### **What will happen to the results of the research study?**

This study is being carried out as a means of identifying what barriers exist for Disabled people in GRT communities. This information may later be used to inform future research into addressing some of the identified barriers. The findings of this study will be published in academic journals and presented at conferences. If you wish to receive a summary of the research findings please contact the Lead Investigator (details below).

### **Who is organising the research?**

This research has been approved by the University of Worcester Institute of Health and Society Ethics Committee, and has been organised by researchers within the institute.

### **What happens next?**

If you do decide to take part, please send the Consent Form (sent separately) back to Dr Peter Unwin - [p.unwin@worc.ac.uk](mailto:p.unwin@worc.ac.uk), together with any personal or generalised views / reflections about GRT communities and Disabled people. Alternatively, Peter will arrange either a telephone or face to face interview with him or Alex Jones, Research Assistant - [alexandra.jones@worc.ac.uk](mailto:alexandra.jones@worc.ac.uk)

***Thank you for taking the time to read this information***

## Appendix 5: Survey Questions for GRT Community

### Questions for social media survey

The University of Worcester and Shaping Our Lives disability charity are doing some research about Disabled Gypsy, Roma and Traveller people. We would be very grateful if you could answer a short survey below.

I am (please tick):

Irish Traveller

Scottish Gypsy Traveller

Welsh Gypsy

English Gypsy

Roma

If Roma, from which country originally?

I am (please tick):

Female

Male

My age:

If you or a family member has a disability like a long-term health problem, poor hearing/sight, problems with walking or something else, please answer below questions:

1. Where would you go to get help? (tick any you have tried):

- Family member
- A trusted person in your community
- A local Traveller organisation
- Irish centre
- Your GP
- Hospital/A&E
- Citizens Advice Bureau
- Local council services (like Traveller liaison officer)
- Other, please tell us here:

2. Was / is getting help easy (please circle)?

Yes / No

3. If it was easy, why?

4. If it was difficult, why?

5. Have you tried to get help from a charity for Disabled people?

Yes/No

6. If yes, was it (tick any help you have had):

- To get equipment to help e.g. a ramp to help to get up steps
- Advice about the health problem or disability
- Advice about benefits
- Meet other people with similar long-term health problems or disabilities
- Other help, please tell us here:

## Appendix 6: Focus groups and interview questions

### Missing Voices Research Study

#### University of Worcester and Shaping Our Lives

#### Questions for meetings and focus groups with Disabled people from Gypsy, Roma and Traveller communities

1. Which communities are you from, Gypsy, Roma or Traveller?
2. What do people from your community think about disability?
3. Do you use any definition for disability?  
For example, there is a definition in the Equality Act 2010 that defines a Disabled person as:  
"if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities."
4. What words do you use to describe Disabled people?
5. What are the main problems that Disabled people in your community experience?
6. Where would they go for help and why?
7. What makes it difficult to seek help?
8. How do you feel about approaching a service provider such as a Deaf or Disabled People's Organisation to get help? (Do you know what a Deaf and Disabled People's Organisation is?)
9. How do you feel about approaching service providers such as doctors, social workers, lawyers for help?
10. Are there services (charitable or public) that are easy for people from your community to use? If yes, why is this?
11. Do you think Disabled people in your community get useful information about services that can help?
12. What is the best way to provide information?
13. Are the voices of Disabled people from your community being heard:
  - A) In your community?
  - b) In the wider Disabled people's community?

14. Do you think Disabled people from your community would benefit from meeting other Disabled people from other communities, for example, by joining a campaigning or support group of Disabled people from a range of different communities?

A) If no, why not?

B) If yes, how?

15. Could Disabled people from your community benefit from:

Advice about rights for Disabled people

Advice and guidance about benefits

Advice and guidance about services

Advocacy or support

Personal budget and direct payments administration

Buying access equipment

Training in using access equipment

Social and leisure activities

Volunteers

Other

Is there anything else you would like to add?

Any other comments about your accommodation, lifestyle etc....

## Appendix 7: Links to websites showing project promotion

University of Worcester press release:

<https://www.worcester.ac.uk/about/news/2019-university-research-will-look-at-experiences-of-Disabled-people-within-gypsy-roma-and-travelling-communities>

Shaping Our Lives press release:

<https://www.shapingourlives.org.uk/resources/our-resources/our-latest-work/including-missing-voices-hearing-the-voices-of-Disabled-people-in-gypsy-roma-and-traveler-communities>

Romani Arts promotion:

<http://www.romaniarts.co.uk/including-missing-voices/>

Cardiff Third Sector Council:

<https://www.c3sc.org.uk/news/6319-including-missing-voices>

Travellers Times promotion:

<https://www.travellerstimes.org.uk/news/2019/08/missing-voices-researchers-want-hear-Disabled-gypsies-roma-and-travellers>

Viewpoint website promotion:

<http://www.hertsviewpoint.co.uk/news-stories-collection/shaping-our-lives-insight-including-missing-voices>

Inclusion London promotion:

<https://www.inclusionlondon.org.uk/campaigns-and-policy/act-now/including-missing-voices-listening-to-Disabled-people-in-gypsy-roma-and-traveller-communities/>

## Appendix 8: Organisations providing advice and services to GRT communities and community connectors

- Travelling Ahead: Gypsy, Roma and Traveller Advice & Advocacy Service / Teithio Ymlaen: Gwasanaeth Cyngor ac Eiriolaeth Sipsiwn, Roma a Theithwyr, GTP Cymru, 12 North Road, Cardiff CF10 3DY. <http://www.travellingahead.org.uk/contact/>
- The Romani Cultural and Arts Company, Temple Court, 13A Cathedral Road, Cardiff, CF11 9HA <http://www.romaniarts.co.uk/>
- Ms. Rosemary E. Kostic Cisneros - [Faculty Research Centre for Dance Research \(CDaRE\)](#) Parkside, Institute for Creative Enterprise (ICE), Coventry University, CV1 2NE Coventry. <https://pureportal.coventry.ac.uk/en/organisations/faculty-research-centre-for-dance-research-cdare>
- Travellers' Times, c/o Rural Media, Packers House, 25 West Street, Hereford, HR4 0BX. <https://www.travellerstimes.org.uk/>
- Gypsies and Travellers , Wales Trowbridge Community Centre Cardiff CF3 1RU <https://gtwales.org.uk/welfare/>
- Friends, Families and Travellers, 113 Queens Rd, Brighton BN1 3XG. [fft@gypsy-traveller.org](mailto:fft@gypsy-traveller.org)
- Travellers Movement, The Resource Centre, 356 Holloway Road, London N7 6PA. [info@travellermovement.org.uk](mailto:info@travellermovement.org.uk)