

# Who Cares? Caring in Gypsy, Roma, and Traveller Communities.

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**Recent Research Findings – Physical  
and Mental Health in Gypsy, Roma,  
and Traveller Communities**

**How can we improve?**



**My Background**



**My Lack of Knowledge**

# A Little Less Conversation, a LOT More

## Action

**Carers in general are absent from the many reports of the last two decades on health and care issues.**

**The key carer strategy and policy documents that do exist do not mention the special circumstances of carers in Gypsy, Roma and Traveller Communities.**

**The DHSC (2018) *Carers Action Plan* did not mention them and neither does the latest House of Commons Briefing Paper *'Informal carers: health and wellbeing'* (2024)**

# Hidden and Ignored

**Carers in Gypsy , Roma, and Travellers  
Communities are hidden and ignored.**

**Things are hard enough for all carers  
financially and emotionally (Carers UK,2023)  
but the plight of Gypsy, Roma, and Traveller  
carers is all the more so, overlaid by issues of  
discrimination and ignorance on behalf of  
politicians and professionals.**

## Four Recent Reports

The Missing Voices of Disabled People in Gypsy, Roma and Traveller Communities (2020)

Inequalities in Mental Health Care for Gypsy, Roma, and Traveller Communities (2023)

Understanding Patient Data (2024)

Gypsy/Traveller Carers (2024)



[https://www.youtube.com/watch?v=PB5b7d\\_tXjw&t=5s](https://www.youtube.com/watch?v=PB5b7d_tXjw&t=5s)



**“We are Terrible Strangers  
to each other...”**

**“Education, Education,  
Education”**



# ‘Missing Voices of Disabled People’ -

## Carer Voices:

There was a general consensus across all focus groups that Gypsy, Roma, Traveller families do ‘care for their own’ where they can.

“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. “

(Community Connector, Scotland)

# 'Missing Voices' Carer Voices:

"Wouldn't your daughter's needs be better met in a house?"  
I said "I have no doubt about that, I said 100%, 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.

Why can't her needs be met on a site where I have carers and  
everything round about me to help me?"

I turned the table, and said to the man that was leading the  
board, "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... What if I asked you to move onto a site?  
...Leave your environment, move onto a site...because that's  
what you're trying to do to me." (Scottish Gypsy Traveller  
Carer)

## 'Missing Voices' - Carer Voices:

"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)

## 'Missing Voices' - Carer Voices:

One scenario encountered by the research team involved an older man who was cared for by his family on a small roadside 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.

## 'Missing Voices'- Carer Voices:

However, 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, stoicism, or perhaps a tendency to 'over-protect', is always in the best interest of individual Disabled people.

## 'Missing Voices'- Carer Voices:

A Scottish Gypsy Traveller focus group also thought that the 'authorities' had a 'one size fits all' view of all our 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."

# 'Missing Voices'- Carer Voices:

" ... 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."

(Scottish Gypsy Traveller)

# 'Missing Voices' - Carer Voices:

The review found little evidence that families and carers reached out to preventive services and concluded that, more often, when in mental distress, they 'reached out for the rope'.

The general health and welfare of Gypsy, Roma, and Traveller communities has been well documented in a range of research initiatives (e.g., Van Cleemput, 2018; Rogers and Greenfields, 2017; Unwin, Meakin and Jones, 2020; Office for National Statistics, 2022), yet nothing much has changed in recent years, and outcomes across both physical and mental health remain lower than all other ethnic minorities in the UK.



# Lack of Community Knowledge about Rights under Legislation

Many Gypsy, Roma, and Traveller communities and professionals were unaware of their protected characteristics under the Equality Act, 2010, and practice has failed to provide effective levels of protection under this legislation.

The Care Act, 2014, was never mentioned.

# Cultural Taboos

‘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).

# Cultural Taboos

'...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).

# Best Practices Found

## **Exchange House, Dublin**

Young people informed staff that parents would be their first port of call if mental health was a problem - hence parents are educated about appropriate responses so that they can help or 'hold' their children, while professional help is sought. Response times to getting professional help seemed swift, particularly when compared to reported delays in the UK system.

# Best Practices Found

**GATE Herts**, in partnership with the Public Health Team at Hertfordshire County Council, developed a Bereavement and Suicide Support Service to combat local challenges associated with the high levels of suicide and subsequent 'copycat' suicides among Gypsy and Traveller families.

# Best Practices Found

**Leeds GATE** created their own suicide prevention package, *'Keeping your Friends and Family Safe'*, which is 'user friendly' and has contemporary video clips and role play based on local lived experience. The absence of literacy in many families prevents take up of services and leads to avoidance for fear of not being able to understand what happens in services.

# Understanding Patient Data ( Due 2024)

**NHS Commissioned to find out the preferences of Gypsy, Roma, and Traveller people regarding ethnic classification / collection of data UK wide.**

**11 Focus Groups /Approx. 100 Surveys**

# Mixed views to date

Ranging from “It’s very important to collect our data and know our health issues”

To

“Don’t collect ethnicity data – just treat us as human beings”



# Understanding Patient Data (2024)

Again, carers' issues per se not highlighted but the findings have resonance for carers regarding :

- Lack of belonging in a service where, from the outset your ethnicity is not listed
- Many experiences of overt and covert discrimination from Receptionists to Consultants

# Understanding Patient Data (2024)

Issues of a lack of education in health professionals

Lack of understanding about families visiting hospitals

Lack of understanding of death and dying norms

Lack of interpreters (Roma)

Not listening/ Disrespecting carer opinions

Not explaining health issues / plans clearly

Digital poverty/ illiteracy

# Understanding Patient Data (2024) -

## Quotes

**“To know more about our traditions and that women are not comfortable with male interpreters, male doctors or male family members being present”**

**“My main issue is the stereotypes that are believed by some NHS staff members. No, we're not all violent and not everyone who is a Gypsy or a Traveller is 'traditional'. The security that works within NHS hospitals are usually the worst culprits.”**

# Understanding Patient Data (2024) -

## Quotes

**“Sometimes I’m worried about telling the hospital I’m a Traveller in case of discrimination and prejudice. I don’t want that interfering with my treatment. I’m also worried about the information being shared elsewhere and it’s not always safe for people to know you’re a Traveller. In living memory Gypsies and Travellers were murdered in the holocaust and it’s a worry that your names on a list and could be used against you in the future.”**

# Understanding Patient Data (2024) - Quotes

**“I went to the doctors with my sister in law, and she didn't speak English, so I was there for her to translate. The doctor was like –‘No, I have to call a translator.’ “**

**“There’s a lack of professionals' interest in Travellers plus unwillingness to allocate resources, viewed as better spent on other patients.”**

# Understanding Patient Data (2024) - Quotes

**“I’ve had cancer and they’re keeping me alive. I’ve had several major illnesses in the past and I’ve been grateful for their help and expertise.”**

**“I told her [*the doctor*], and she listened, and she sees my dad on a regular basis and my mum, and because they're diabetics, and there's new system where you've got to go online download or have to order a repeat prescription, and they've made them aware that they can't do that because he has no internet.”**

# Understanding Patient Data (2024) - Quotes

There's enough  
research, **action** is  
needed to close known  
inequality gaps

# Gypsy/Traveller Carers Briefing Sheet 15 (MECOPP, 2020, pp.5-6)

The proportion of Gypsy/Travellers providing more than 50+ hours of care per week is twice that of the general population. Despite the preponderance of 'heavy duty' caring within the community, Gypsy/Traveller carers continue to experience significantly lower levels of access to mainstream carer support services.



# Contributory factors include:

- ▶ Lower levels of self/identification as a carer as caring for another family member is very much seen as a natural and normal part of family and community life;
- ▶ Lack of digital/literacy which impacts significantly on the ability to search for information and to navigate often complex referral pathways for services;
- ▶ Lack of confidence in assessment processes which fail to take into account cultural aspects of their identity, for example, strict adherence to gender roles and what constitutes acceptable behaviour;

# Contributory Factors (Cont'd)

- ▶ Concerns of negative stereotyping about the community in general and the need experienced by many individuals to keep their identity 'secret' for fear it would impact on how they were perceived;
- ▶ Lack of understanding of the deeply private and cohesive nature of family life within the community leading to a reluctance for 'outside' services to be brought in;
- ▶ Lack of understanding of the complexity and nature of caring situations where care responsibilities are often shared between different members of the family; and,
- ▶ Lack of flexibility within traditional services which fail to take into account the 'nomadic' lifestyle which is intrinsic to identity

# Mecopp's Positive Examples

- The value of a trusted community intermediary cannot be overstated. Relationships built on mutual trust and understanding have been demonstrated to be the most effective means of engaging with, and supporting, the Gypsy/Traveller community.
- Evidence from the Scottish Parliament Equal Opportunities Committee Enquiry highlights that trusting relationships can be built and fostered by practitioners willing to work outside their professional role, for example, health workers willing to assist individuals in completing welfare benefit or passport applications.

# Mecopp's Positive Examples

- Trusted workers also provide cultural knowledge and insight to support positive and mutually beneficial relationships with a wide range of practitioners. Outcomes include increased accessibility and appropriateness of services, increased levels of confidence in mainstream service provision and higher take-up of support.
- Involving Gypsy/Travellers in both general awareness raising of their culture and community and more specifically, training on Gypsy/Traveller carers has also proven to be an effective and very productive means of building understanding and improving trust with both service providers and policy makers alike. This also has the additional benefit of capacity building within the community itself.

## Mecopp Conclusion

The barriers experienced by Gypsy/traveller carers in accessing services together with the disparities in health, accommodation, employment and education when compared to the general population can mean that the impact of caring for another individual on the carers' health and wellbeing is amplified.

# My Conclusions – How can we improve?

We must **WANT** to improve – people in this room can all do something here!

**Action** is needed not just more Research

Most informal carers are low down on national and local priority list- Gypsy, Roma and Traveller carers are not even on that list!

The current Government will be more empathic to ethnic minority care issues but are unlikely to prioritise carer issues

Local Traveller Organisations might usefully seek funds to develop services for carers, given their neglect within communities to date

Local and National Traveller organisations might challenge why Gypsies, Roma, and Travellers are not routinely included in carer strategies / policies at all levels. People in this room can challenge any omissions in their own strategies/ policy/ practice.

‘Education, Education , Education’ might start with local carer and statutory organisations so that we do not remain such “Terrible Strangers to Each Other”

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