

Briefing Sheet

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Gypsy/Traveller Carers



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Introduction

This briefing paper will explore the needs and experiences of informal carers within Gypsy/Traveller communities in Scotland. Very little research currently exists on both the nature and extent of informal caring within these communities. Where possible, we have drawn on sources such as evidence provided by the community and other stakeholders to the Scottish Parliament Equal Opportunities Committee¹ and data generated by the 2011 Census. This has been supplemented by grassroots work undertaken by MECOPP² through the Gypsy/Traveller Carer Project in four geographic areas: Edinburgh and the Lothians; Perth & Kinross; and, Mid and North Argyll. We have also drawn on more general information included in the 2019 House of Commons Library Briefing Paper³. Although the data relates primarily, though not exclusively, to England, there are common themes and in the context of this Paper, we pay particular attention to 'health'.

Terminology

Gypsy/Travellers were recognised as a distinct ethnic group and so afforded protection under the Race Relations Act (1976) in 2008 following a successful legal challenge. As such, they are also protected under the provisions of the Equality Act (2010). The term 'Gypsy/Traveller' is used by the Scottish Government. However, it covers a range of distinct identities and people may identify as Scottish Traveller, Traveller, Romany Gypsy, Gypsy, Roma, Irish Traveller or Nachin. Just as some Scottish people can be offended if called English some Travellers, for example, can be offended if called 'Gypsy'.

Gypsy/Traveller Carers

The 2011 Census was the first to include Gypsy/Travellers as a separate ethnic category enabling baseline data to be captured across a range of indicators such as health, education, employment, accommodation and caring responsibilities.

Information taken from the Census records 4,200 people identifying themselves as 'White: Gypsy/Traveller' with 492/11.7% of them having a caring responsibility. However, these figures are thought to be an underestimate due to the reluctance of the community to self-identify in the Census. In part, this may be due to a lack of understanding of the purpose of the Census and to a historical mistrust of authorities and official bodies. Organisations working with Scottish Gypsy/Travellers estimate that the actual figure is between 15,000 – 20,000 people.⁴

If this figure is accepted, the number of potential carers with the community would increase to between 1,200 and 1,600 based on 8% of the population having a caring responsibility at any one time.

¹ The Scottish Parliament Equal Opportunities Committee 3rd Report, 2012 (Session 4) *Gypsy/Travellers and Care* September 2012

² <https://www.mecopp.org.uk/gypsytraveller-carers-project>

³ House of Commons Library, Briefing Paper Number 08083, *Gypsies and Travellers*, Hannah Cromarty 2019

⁴ Cited in *On the Margins: Local authority service provision for Scottish Gypsy/Travellers* Amnesty International 2012

The following table provides a breakdown by local authority area of the number of Gypsy/Traveller carers self-identifying in the 2011 Census.

Local Authority	1 – 19 hours care per week	20 – 49 hours care per week	50+ hours care per week	Total
Aberdeen City	18	5	9	32
Aberdeenshire	7	5	16	28
Angus	5	8	8	21
Argyll & Bute	2	5	10	17
Clackmannanshire	5	5	7	17
Dumfries & Galloway	3	1	6	10
Dundee	4	1	4	9
East Ayrshire	2	1	3	6
East Dunbartonshire	1	0	3	4
East Lothian	1	0	0	1
East Renfrewshire	0	0	0	0
Edinburgh City	11	6	15	32
Eilean Siar	1	0	0	1
Falkirk	8	9	9	26
Fife	11	9	22	42
Glasgow City	18	4	11	33
Highland	13	7	12	32
Inverclyde	0	0	0	0
Midlothian	2	2	2	6
Moray	2	1	6	9
North Ayrshire	1	4	1	6
North Lanarkshire	5	2	8	15
Orkney	0	0	0	0
Perth & Kinross	11	17	32	60
Renfrewshire	4	2	2	8
Scottish Borders	5	1	5	11
Shetland Islands	0	0	0	0
South Ayrshire	1	0	5	6
South Lanarkshire	11	18	2	31
Stirling	3	0	3	6
West Dunbartonshire	5	2	5	12
West Lothian	5	0	6	11
	165	115	212	492

As a percentage and based on the above figures, 33.5% provide care for between 1 – 19 hours per week, 23.4% for between 20 – 49 hours per week and 43.1% for 50+ hours per week. Analysis of the 2011 Census by the Scottish Government also notes that Gypsy/Travellers were more than twice as likely to provide a high level of unpaid care (50 or more hours per week) than the general population. However, the proportion of Gypsy/Travellers providing no unpaid care was slightly lower than the general population as were those providing 1 – 19 hours per week.

It is not possible to determine whether there has been a growth or decline in the number of Gypsy/Traveller carers in the period 2001 (the preceding Census) to 2011, as with other ethnic groups⁵, as this data was not then captured.

Health

Analysis of data from the 2011 Census highlights that Gypsy/Travellers were more likely to report a long-term health problem or disability, despite their younger age profile, than the general population (28% compared to 20%). Similarly, they were also more likely to be limited ‘a lot’ by long-term health problem or disability, 16% compared to 10% within the general population. Higher levels of ‘bad’ or ‘very bad’ general health were also reported. Taking into account age-standardisation across different ethnic groups, Gypsy/Traveller women recorded twice the rate of long-term health problem or disability than women within the ‘White Scottish’ ethnic group. There were similar findings for Gypsy/Traveller men who recorded almost twice the rate.

Key points to note include⁶:

- ▶ Gypsy/Travellers were more likely to have one or more long-term health conditions (37% reported at least one condition compared to 30% of the population as a whole and they were twice as likely to report 3 or more health conditions, 6% compared to 3%);
- ▶ 69% of Gypsy/Travellers reported ‘good’ or ‘very good’ health compared to 82% of the general population;
- ▶ Gypsy/Travellers were nearly three times more likely (15%) to report ‘bad’ or ‘very bad’ health compared to 6% in the general population and five times more likely to report ‘very bad health’.

Analysis of the Census data accords with a number of studies which found that Gypsy/Travellers have higher mortality rates, morbidity and co-morbidities, lower levels of child immunisation and a higher prevalence of anxiety and depression. Contributory factors are thought to include poor and inadequate accommodation, the impact of discrimination and racism, poorer health literacy and a lack of understanding and awareness on the part of health professionals leading to poorer health outcomes overall.

This is illustrated most starkly by life expectancy. Whilst the life expectancy of Scottish Gypsy/Travellers is unknown, research evidence provided to the Scottish Parliament Equal Opportunities Enquiry into Gypsy/Travellers and Care⁷ cites it as 55 for men. The Equality and Human Rights Commission (EHRC) has estimated that in Britain, life expectancy for Gypsy/Traveller men and women is 10 years less than the general population.⁸

At a local level, research conducted by the Edinburgh Access Practice (EAP)⁹ showed that the Gypsy/Traveller community had higher than average levels of obesity, hypertension, risk factors for diabetes, heavy alcohol use and/or smoking and risk of cardio-vascular disease when compared with the general population.

⁵ https://static1.squarespace.com/static/5c06d635506f62ec834460/t/5c13d6354fa51a4ff9916883/1544803897276/mecopp_briefng_sheet_07.pdf

⁶ see <https://www.gov.scot/publications/gypsy-travellers-scotland-comprehensive-analysis-2011-census/pages/6/>

⁷ <https://www.parliament.scot/parliamentarybusiness/CurrentCommittees/54885.aspx>

⁸ Equalities and Human Rights Commission 2009: Gypsies and Travellers: simple solutions for living together <https://www.equalityhumanrights.com/en/gypsies-and-travellers-simple-solutions-living-together>

⁹ Cited in The Scottish Parliament Equal Opportunities Committee 3rd Report, 2012 (Session 4) *Gypsy/Travellers and Care* September 2012

Evidence presented to the Scottish Parliament Equal Opportunities Committee Enquiry highlighted that Gypsy/Travellers often sought treatment at the last minute relying on GP out of hours' services or accident and emergency departments. Treatment was often reactive rather than proactive whereby the immediate issue was addressed but the underlying cause was not investigated.

Other determinants of health and wellbeing such as accommodation employment and education also have a detrimental impact on Gypsy/Traveller communities.

It is a common misconception that all Gypsy/Travellers live in caravans. Only 14% of the community do so. Gypsy/Travellers are more likely to live in overcrowded accommodation, less likely to own their own homes, less likely to have central heating and more likely to live in caravans than the general population.

Key points to note include¹⁰:

- ▶ 33% of Gypsy/Travellers owned their own home compared to 67% of the general population;
- ▶ Gypsy/Travellers were twice as likely to rely on rented social housing (40%) compared to 21% in the general population;
- ▶ 14% of Gypsy/Travellers lived in a caravan or other mobile or temporary structure compared to less than 1% of all households;
- ▶ A lower proportion of Gypsy/Travellers (43%) lived in housing compared to 63% of the general population;
- ▶ Gypsy/Traveller households were more than twice as likely (24%) to live in overcrowded accommodation compared to 9% of all households; and
- ▶ Gypsy/Traveller households were more than twice as likely (5%) to have no central heating compared to 2% of all households. They were also more likely to have electric central heating.

For those living on official Gypsy/Traveller sites in caravans, chalets or static caravans little or no account has been taken of disability/reduced mobility in the built environment or accommodation provision.

Information from the 2011 Census also shows that Gypsy/Travellers fare particularly badly in terms of employment. Gypsy/Travellers were less likely to be economically active, more likely never to have worked, more likely to be in 'elementary' work and to be in the lowest social grading.

Points to note include¹¹:

- ▶ 49% of Gypsy/Travellers aged 16+ were economically active compared to 63% of the general population ('economic activity' denotes whether an individual was in work or actively seeking work in the week before the Census – it is a measure of whether an individual is an active participant in the labour market);
- ▶ 20% of Gypsy/Travellers were in elementary occupations compared to 12% of the population as a whole;
- ▶ Gypsy/Travellers were more likely to be long-term sick (15%) and home-makers (11%);
- ▶ Only 10% of Gypsy/Travellers were retired compared to 22% of the general population (Gypsy/Travellers have a younger age profile); and,
- ▶ 51% of Gypsy/Travellers aged 16-64 were in the lowest social grade 'DE' – semi-skilled, unskilled manual or lowest grade workers or those on state benefits or unemployed – compared to 26% of the whole population.

¹⁰ see <https://www.gov.scot/publications/gypsy-travellers-scotland-comprehensive-analysis-2011-census/pages/6/>

¹¹ see <https://www.gov.scot/publications/gypsy-travellers-scotland-comprehensive-analysis-2011-census/pages/6/>

Gypsy/Travellers self-report enduring problems with the formal education system typified by instances of bullying and harassment leading to lower levels of attendance and attainment. Data shows that 50% of Gypsy/Travellers had no formal qualifications compared to 27% of the population as a whole¹². The life-long impact of this is self-evident (see information on employment above).

The impact of discrimination and racism experienced by the community cannot be overstated. The overall conclusion of the 2010 Scottish Social Attitudes Survey was that Gypsy/Travellers are the subjects of widespread discriminatory attitudes. For example, 47% of respondents believed that a Gypsy/Traveller would be unsuitable as a primary school teacher, down by 1% in 2006.

Informal Caring

It has already been noted that 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;
- 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.

The importance and impact of this last factor is one which is consistently raised by members of the community. Evidence given to the Scottish Parliament Equal Opportunities Committee Enquiry noted that delays in the assessment process, sometimes of many months, can mean that the carer and/or cared for person has moved out of one local authority area into another before a support plan has been completed. In some instances, this may require another assessment to be undertaken or a support plan to be put in place, the outcome of which may vary according to local circumstances.

For many Gypsy/Travellers, the only option available when caring for a family member who is disabled or has a long-term condition is to move into 'bricks and mortar' housing to ensure access to, and continuity of, support and services. The loss of this aspect of cultural identity can impact significantly on an individual's mental health.

¹² see <https://www.gov.scot/publications/gypsy-travellers-scotland-comprehensive-analysis-2011-census/pages/6/>

For those Gypsy/Travellers who continue to live in static/trailers or chalets, these forms of accommodation can be particularly ill-suited to the provision of aids and adaptations within the home. The built environment of the home may not be suitable for the installation of certain types of equipment and the often limited space can make storage problematic. Similar problems are evident within chalet accommodation. Sites, themselves, often do not take into account issues of accessibility for disabled individuals and individuals with reduced mobility. There is growing recognition that sites do not take into account 'future proofing' for an ageing population.

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.

Conclusion

Whilst the issues noted above are considerable, good practice has developed in Scotland which supports transferable learning and replicable approaches.

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. Trusted workers provide a single point of contact for the community helping them to access and understand often complex information, navigate systems and processes and acting as liaison and advocate.

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.

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.

Support for Gypsy/Traveller Carers

The MECOPP Gypsy/Traveller Carers' Project supports informal carers in four geographic areas: Edinburgh and the Lothians; Perth & Kinross; and, Mid and North Argyll. The project provides a wide range of services including advocacy and casework support; awareness-raising training; publications and resources; arts based work; and, supporting civic and civil engagement for Gypsy/Traveller women.

Further details of our work can be found at: <https://www.mecopp.org.uk/gypsytraveller-carers-project>