

Response to the Scottish Government's Consultation on Carer Legislation

1. Introduction

MECOPP Gypsy/Traveller Carers' Project welcomes the opportunity to comment on the Scottish Government's proposals to improve outcomes for carers and young carers in Scotland. As Scotland's only Black and Minority Ethnic (BME) care organisation we have been working directly with Gypsy/Traveller carers since May 2011. We currently work with carers of all ages from the Gypsy/Traveller community who live on sites and camps, and in housing, in three localities the Lothians, Perth and Kinross and Mid and North Argyll. We also work with service providers in each area to increase their capacity to respond more appropriately to the needs of carers from the Gypsy/Traveller community.

In addition, over the last eighteen months we, in conjunction with Gypsy/Traveller carers, have had the pleasure of working with Scottish Parliament Equal Opportunities Committee (EOC) during their two recent Inquiries – 'Gypsy/Travellers and Care' and 'Where Gypsy/Travellers Live'. The Gypsy/Travellers and Care Inquiry took evidence from a number of service providers and community members from across Scotland, and summarises many of the issues faced by carers in the Gypsy/Traveller community on a daily basis.¹

This consultation response is intended to complement, rather than duplicate, the verbal and written evidence already submitted to the EOC Care Inquiry. We have structured this response around the Government's proposals and the main issues raised by Gypsy/Traveller carers in our daily advocacy and casework.²

2. Carer's Support Plan

2.1 Assessment

The vast majority of Gypsy/Traveller carers consulted have never undergone a Carer's Assessment. Whether the assessment is renamed as a Support Plan or not is unlikely to make any difference to these carers.

A lack of trust with social workers, and Councils at large, means that there is a reluctance among carers to ask for support. None of the carers report positive experiences with their Council, with almost all repeating the phrase, "*it's like hitting your head against a brick wall*", and many feel that they are blacklisted by the Council. One carer said, "*I never realised that being a carer meant taking on the Council*". That assessments are carried out by social workers is a major barrier to Gypsy/Traveller carers, who have poor relations with local Councils and a real fear of social work involvement.

One carer suggested that the visiting health worker to the site she lives on is better placed to carry out an assessment of her needs than a social worker. She believes that the health worker is more aware of her needs for improved wellbeing, as she is able to take a more holistic approach, and she would be open to doing an assessment with her. Other carers suggested that there is a need to have independent organisations, such as MECOPP, doing the assessments so that they do not have to deal with the Council themselves.

¹ <http://www.scottish.parliament.uk/parliamentarybusiness/CurrentCommittees/49020.aspx>

² For more information about the MECOPP Gypsy/Traveller Carers' Project please contact Michelle Lloyd, Programme Manager michelle@mecopp.org.uk

2.2 Portability

The issue of portability of assessment appears to be more of an issue for service providers and local authorities than it is for Gypsy/Traveller carers themselves. Many of those consulted are based in one area for the majority of the year (often because of ill-health or disability and lack of facilities on sites), so portability is not a major concern for them. However, surveys and interviews with local authority staff and service providers show that they consider portability to be a challenge when supporting Gypsy/Travellers. There is a danger that this becomes an 'excuse' for not providing services to Gypsy/Travellers – as one carer commented, *“there’s an attitude of ‘don’t give them anything as they’ll only move on after a while anyway’”*.

This perhaps ties in with a lack of understanding of Gypsy/Travellers which has also been evident in interviews with service providers. Comments such as, *‘We don’t have any real Travellers here’*, and talk of *‘ex-Travellers’*, have been repeated on various occasions, showing that Gypsy/Travellers are only recognised as such if they are constantly on the move.

However, the portability of care packages was raised by one carer who had a bad experience of moving from one local authority to another. Where she lived previously, she felt she was being inundated with offers of help and that she was *“practically turning people away”*. However, having taken the decision to move to another area which she thought would provide a better environment for her children she was shocked to find that none of the same support was available. She puts this down to prejudice within the new local authority.

The Scottish Parliament’s Equal Opportunities Committee inquiry on Gypsy/Travellers and Care, called for *“the portability of single-shared assessments and care plans and consistency of care provision”* to benefit all individuals when relocating.³

2.3 Key points:

- That assessments are carried out by social workers is a barrier to Gypsy/Travellers seeking support;
- Assessments could be more accessible if they were carried out by trusted health workers or independent organisations;
- Negative experiences and feeling of being blacklisted means there is little trust between Gypsy/Traveller carers and local authorities;
- Portability of care plans would be beneficial, though this is not a major concern among the carers consulted, many of whom do not travel on a frequent basis.

3. Information and Advice

3.1 Lack of accessible information

There is a lack of accessible information about support available to Gypsy/Travellers. Many have said that without MECOPP, they would not have known about the support available to them. Information materials are generally not accessible to the Gypsy/Traveller community, where literacy levels are low, and what is there does not seem to reach community members. Carers said they have not received leaflets about support, and two carers are further isolated by a lack of landline and internet connection on their site. When asked how they find out about support available, the reply was *“doctor surgeries”* or *“through MECOPP”*.

³ Scottish Parliament EOC 3rd Report, 2012 Gypsy/Travellers and Care, paragraph 57

Social care jargon is a further barrier to Gypsy/Travellers accessing information. As the majority of carers consulted are not accessing social care services, much of the language used is unfamiliar to them, so they are often left unsure what to ask for.

Some carers have expressed their preference for information to be provided verbally. Information materials, then, are most effective when they are supported by face-to-face discussions. There was also a suggestion that there could be targeted information on Facebook as a lot of people, particularly the younger generation, are on Facebook.

Many carers have expressed their view that having a single point of contact/telephone number would be helpful.

3.2 Discriminatory Attitudes

The issue is not only about a lack of information but also a lack of engagement by service providers. Several carers have relayed their experiences of receiving incorrect information or advice from social workers, or being 'put off' accessing services, which they put down to discriminatory attitudes.

For example, one carer reported that it took her five years to get any help, despite having numerous visits from the same social worker. It was only when a MECOPP worker became involved that support was set up to help the carer look after her elderly mother who has dementia. The carer feels that there was an attitude of "*Gypsy/Travellers can look after themselves*" from the social worker.

One wheelchair user struggled for two years to have adaptations made to her chalet so that she did not have to rely on family members to lift her in and out of her home. Initially told by her Council that they did not have the funds available, a lift was installed only after she participated in the Scottish Parliament's Equal Opportunities Committee inquiry into Gypsy/Travellers and Care.

Another carer also had difficulties securing essential adaptations to her home. "*There are seven in my family and each one has medical problems. Manhandling my daughter and lifting and transferring her from place to place has caused damage to their backs, spines, and shoulders. I have arthritis on my spine due to manhandling my daughter*".

One carer was told by a social worker that direct payments would be "*too much hassle*" because of the paperwork involved for the carer who struggles with reading and writing. "*They do try to talk you out of it. They come up with so many rules and regulations to put you off*". However, she was fortunate enough to meet another social worker who was more encouraging and able to offer support with the paperwork, and she is now making steps towards accessing direct payments.

Another carer interested in accessing direct payments was also told by an Occupational Therapist that payments would be "*too much hassle*" could not be used to pay for relatives to provide care, which meant the carer did not pursue this route further.

3.3 Key points:

- Gypsy/Traveller carers feel that there is a lack of information available to them;
- Discriminatory attitudes from service providers means that carers often struggle to receive correct information or advice;
- A single point of contact would be helpful for carers;
- Information materials need to be supported by outreach work.

4. Support to Carers

4.1 Short breaks

Many carers welcome the opportunity to have a break. However, there is a strong sense among Gypsy/Traveller carers that traditional respite services are not relevant to them. None of the carers would consider residential care for the cared-for person to be an option, or for their personal care to be carried out by a stranger.

Rather than being offered a 'break from' the cared-for person, many carers would welcome the opportunity to have a 'break with' them. One former carer spoke about how she would have liked support for her and her brother, who she cared for, to visit family down south. This would have given her a break from her caring role, as her family would have been able to take over the personal care work, without the guilt and anxiety she would have felt leaving her brother in a residential home. Several other carers also suggested that being able to visit family elsewhere in the country would provide them with some respite that is culturally appropriate and ultimately more beneficial for them.

One carer, who cares for her daughter, spoke about the difficulty she had trying to organise respite for her daughter. Her local Council offered to arrange a trip for her daughter, which both the carer and her daughter were excited about. However, the carer did not want her daughter to go away without a family member being with her, and put it to the Council that one of her other daughters would also attend to help with care. However, the Council advised that only their staff could go on the trip. Worried about sending her daughter away without someone who knows and understands her needs, the carer cancelled the trip.

4.2 Services not relevant

There is a sense among carers that the support currently available is not relevant to them. One male Gypsy/Traveller who provides care for his brother, said that he was not interested in accessing services such as carer's cafes, as "*they are more for women*". Instead, he would prefer to receive help with practical tasks, such as chopping wood, which would relieve some of the burden on him. He also commented that poor relations with the settled community act as a barrier to services, as it is seen as something for 'them': "*we stay away from them, they stay away from us*".

Another carer who did seek support said that what she was offered was not right for her. She was looking for help with her accommodation situation, but after approaching social work for support, was offered massage vouchers and life coach sessions, neither of which she wanted or found helpful.

Some of the support needs identified include: driving lessons, help with transport costs, independent advocacy, the need for adaptations on sites, provision of a landline and/or internet access to sites, health care (of carers).

4.3 Key points:

- Carers expressed their preference for breaks away with the cared-for person, rather than a break away from them;
- There is a strong cultural preference for caring to be kept within the family, which means that family members want to be involved in breaks for the main carer;
- There is a feeling among carers that services are not relevant to them.

5. Identification

5.1 Caring within family

There is a strong feeling among Gypsy/Traveller carers that caring be kept within the family, and for many it is *“just something you do”*. Many carers were surprised when they first heard about MECOPP’s Gypsy/Traveller Carers’ project, as they did not identify as a carer or use the term to describe themselves.

Many carers feel guilty when talking about themselves and their caring-related struggles. As one carer said, *“It’s more about [the cared-for person] and giving her the life that she wants, not me”*.

All carers felt that personal care should be carried out by family members, and strongly rejected suggestions that this could be carried out by Council employees. One carer said, *“My mother would rather risk harming herself than get personal care from the Council”*.

One carer is employing a personal assistant who is not from the Gypsy/Traveller community to help with her mother. However, the PA is someone who is close to the family and has known the mother for many years. The carer would not want personal care to be carried out by a stranger.

5.2 GPs

GPs are often the first point of contact for carers and the cared-for, and could play a key role in identifying carers. However, there are cases where GP surgeries have refused to register Gypsy/Travellers.

Building trust with GPs is important – Gypsy/Travellers may travel hundreds of miles to see a trusted GP or health worker. The Scottish Parliament Equal Opportunities Report on Gypsy/Travellers and Care, found that, *“... by focusing on developing a trusting relationship between healthcare professionals and Gypsy/Travellers and by increasing Gypsy/Travellers’ own knowledge of healthcare issues, carers and cared-for individuals’ unique support needs could be more effectively identified and met”*.⁴

5.3 Key points:

- Many Gypsy/Travellers do not identify themselves as a carer;
- There is a strong preference for caring to be kept within the family;
- GPs are often first point of contact for carers, but there needs to be trust for Gypsy/Travellers to access their GP.

⁴ Scottish Parliament EOC 3rd Report, 2012 Gypsy/Travellers and Care, paragraph 24