

# HIDDEN CARERS UNHEARD VOICES

**Informal caring within the Gypsy/Traveller community in Scotland**



**This paper shares learning and presents the initial findings from the MECOPP Gypsy/Traveller carers' project. It will also highlight the views and experiences of Gypsy/Traveller carers in three areas of Scotland in 2011/12.**

# MECOPP

MECOPP (Minority Ethnic Carers of People Project) is an independent charity, based in Edinburgh, which provides a range of services to support minority ethnic carers in their caring role. We provide a variety of services from our Carers Centre, including multi-lingual advice and information; advocacy and casework support; individual and group support; education, training and learning opportunities; healthy living programmes; and, practical support in the home through our domiciliary care at home service. We are Scotland's foremost Minority Ethnic organisation working in the field of health and social care. In May 2011, we started a new project working with Gypsy/Travellers in three localities of Scotland: Edinburgh & the Lothians, Perth & Kinross and north Argyll.

## MECOPP and Gypsy/Travellers:

At the start of the Gypsy/Traveller project, we deliberately chose to focus on three areas of Scotland where staff already had strong relationships with Gypsy/Traveller carers and their families. We were very conscious that it takes a considerable amount of time to build up trust and initial funding was only available for one year. With this in mind we had to concentrate on areas where we could 'hit the ground running'. In the Oban area, we have been fortunate to work closely with North Argyll Carers Centre. The MECOPP Gypsy/Traveller project has complemented and greatly enhanced their existing programme of work.

We use community development approaches and our work is multi-dimensional – including outreach work, community-led research, film-making, casework and training. Some of our activities to date have included:

- ❖ Designing and delivering eight awareness-raising training sessions for 116 service-providers across the three areas. Sessions are very participatory

and led by Gypsy/Traveller trainers. Feedback has been extremely positive.

- ❖ Created a powerful new DVD 'Hidden Carers – Unheard Voices' with seven Gypsy/Traveller carers, male and female, speaking openly about the issues they face.
- ❖ Presentations to the Cross Party Group on Carers and the Equal Opportunities Committee (EOC) at the Scottish Parliament, and we will be providing further evidence to the forthcoming EOC review.
- ❖ Direct advocacy and casework support with over 60 carers, increasing awareness of, and confidence in, carer support services.
- ❖ In conjunction with partners, organised regular health and wellbeing events to bring Gypsy/Travellers together in an informal setting to find out more about local health and social care services, as well as trying out relaxation and wellbeing activities.

## Funding and Outcomes:

Funding for the first year was awarded by the Scottish Government Equalities Unit, Carers Unit and NHS Lothian. Our main outcomes were:

- ❖ Increased local and national knowledge of the pattern, nature and extent of informal caring within Gypsy/Traveller communities in Scotland.
- ❖ Increased capacity of partners to respond more appropriately to the needs of informal carers from the Gypsy/Traveller community.
- ❖ Increased knowledge of, and confidence in, carer support services amongst Gypsy/Travellers.
- ❖ Quantifiable improvements in the physical, emotional and financial health of individual Gypsy/Traveller carers.
- ❖ Increased knowledge about the mental health and wellbeing of Gypsy/Traveller carers in Edinburgh & the Lothians.



# Background

Despite a wealth of legislation and guidance to promote equality and human rights, and protect against discrimination, within the UK and Europe, Gypsy/Travellers are arguably one of the most marginalised and isolated communities in Scotland today. In 2008 Scottish Gypsy/Travellers were finally recognised as an ethnic minority in terms of the Race Relations Act 1976, now superseded by the Equality Act 2010. Nevertheless, many Gypsy/Travellers continue to face discrimination and experience wide-ranging inequalities on a daily basis. Trevor Philips, now Chair of the Equality and Human Rights Commission, once referred to discrimination towards Gypsies and Travellers as being *“the last ‘respectable’ form of racism in Britain.”*<sup>1</sup>

In *Caring Together: The Carers Strategy for Scotland 2010 – 2015*, the Scottish Government identified specific communities of carers they knew little about, including Gypsy/Travellers.<sup>2</sup> In May 2011, MECOPP began an innovative new project working with carers within the Gypsy/Traveller community in rural and urban areas of Scotland. We work with any Gypsy/Traveller who has a caring responsibility for a family member or friend and work with carers, of any age, who live in housing, on sites and on roadside camps.

To our knowledge, no previous research in the UK, or further afield, has ever focussed on the specific issues faced by Gypsy/Traveller carers. More generally, as a community Gypsy/Travellers are often referred to as ‘hard to reach’ or ‘seldom heard’, however our research to date tends to suggest that in reality some services do not ‘try hard enough’ to engage with, and provide services to, community members.

**“they’ve always done it, just making decisions ... they never ask, or even take into account, the views of those who actually care for, and live with, her 24/7.”**

**GYPSY/TRAVELLER CARER LIVING IN NORTH ARGYLL**

<sup>1</sup> Phillips, T. (2004) *A Strategy for Gypsies and Travellers* (<http://news.bbc.co.uk/1/hi/england/3751214.stm>)

<sup>2</sup> Scottish Government (2010) *Caring Together: The Carers Strategy for Scotland 2010 – 2015*, Edinburgh

<sup>3</sup> Scottish Parliament Equal Opportunities Committee (2001) *Gypsy Travellers and Public Sector Policies*, Edinburgh

<sup>4</sup> *Ibid*

<sup>5</sup> Scottish Parliament News Release CEQ010/2005, October 2005

<sup>6</sup> Scottish Parliament (2012) *Equal Opportunities Committee Minutes* 2nd Meeting, 2012 (Session 4) Tuesday 7 February 2012

# Policy context

In 2001 the Scottish Parliament Equal Opportunities Committee held an 18 month inquiry into Gypsy/Travellers and Public Sector Policies. This extensive inquiry highlighted for the first time the widespread discrimination faced by many Gypsy/Traveller families in accessing basic services.<sup>3</sup> The inquiry’s 37 recommendations covered health, accommodation, education, policing, criminal justice and promoting good relations. The only recommendation to mention social services was recommendation 33 which stated:

**“Gypsy Travellers should be included in the strategic planning of personal social services, including community care, and the impact of their participation monitored to ensure that their views are considered.”**<sup>4</sup>

In 2005 the Equal Opportunities Committee reviewed progress in meeting these recommendations and expressed disappointment at the overall pace of progress. The Committee found that even where limited progress had been made it was patchy and inconsistent. As Cathy Peattie MSP, at that time the convenor of the committee, said *“...the evidence is clear and unequivocal: the progress made against our earlier recommendations is inadequate and inconsistent, and the pace of progress is far too slow ... We have heard from Scotland’s Gypsy/Travellers and other witnesses that they still suffer from an extreme level of discrimination, vilification and stereotyping and we are not moving fast enough to deliver effective services into this section of our community.”*<sup>5</sup>

Ten years on, many of the 37 recommendations remain just that and very few have been fully implemented.

These two inquiries did not look at issues affecting carers. Our experience suggests that for many Gypsy/Traveller carers, access to social care services, in the statutory and voluntary sectors, remains at best problematic, at worst non-existent.

In January 2012, MECOPP and four Gypsy/Travellers led an Informal Session with the current Equal Opportunities Committee. The session was designed to enable Gypsy/Traveller carers to raise issues of importance to them, their daily struggles, as well as illustrate aspects of the awareness-raising training they have delivered to service-providers. In a subsequent meeting the Committee commended this awareness-raising work and, rather than revisit all 37 recommendations, have now decided to focus on two key issues, accommodation and carers, during this current parliamentary session.<sup>6</sup>

# Issues raised by carers

There is little research evidence directly relating to the experience of Gypsy/Travellers in accessing social care services but in 2006 Cemlyn suggested that Gypsy/Travellers *“with health problems may find that their cultural needs, such as for the involvement of multiple family members in their care, are not easily accommodated.”*<sup>7</sup> Our findings echo this suggestion and further indicate that a lack of recognition and understanding of Gypsy/Traveller culture often results in inadequate responses. Families often reported that they felt like they were being blamed for causing their own problems, as if it was their ethnicity that was the problem, rather than an inappropriate service or lack of flexibility.

In this section we highlight a few examples of the issues raised by carers but this list is by no means exhaustive:

- ❖ Carers were surprised by the MECOPP Gypsy/Traveller Carers' project – most did not identify as a carer or use the term carer to describe themselves. Discussions about rights and entitlements as carers is new to many of those we work with and caring is often seen as 'part of one's family duty'.
- ❖ Isolation, from the wider community and services and sometimes also from their own community, was a recurring theme, particularly for those living in housing. For Gypsy/Travellers, community isolation was identified as an additional barrier for those who have experienced long-term

misunderstanding and prejudice which has led to an increasing distancing from services, including health services. It is not uncommon for Gypsy/Travellers to travel hundreds of miles to see a known GP or trusted support worker, rather than risk rejection at a local surgery or office.

- ❖ Along similar lines, whilst visiting to offer support to carers, MECOPP staff, once trusted, were regularly asked to assist with a wide range of issues including legal matters, policing, education and so on.
- ❖ The majority of Gypsy/Traveller carers are not accessing social care services, voluntary or statutory, on a regular basis, and many had never accessed services at all. General knowledge about carers' rights/entitlements within the community is very low; most carers are not in receipt of Carer's Allowance.
- ❖ Very often families had got into a routine of 'muddling through' or 'making do', both financially as well as with the more practical aspects of caring for a loved one. Those who had tried to access social care services often felt they had not received an appropriate or helpful response and this, in turn, made them reluctant to try again. Cases had often been 'closed' or left hanging with no appropriate care package in place.
- ❖ In their dealings with service-providers and agencies, being listened to seems to be a rare occurrence. Simply creating a space for the carer to be able to talk and be listened to, without being judged, can have a very positive impact. There is often a guarded response or a real reluctance to engage with services unless there is a trusted contact. The impact of a good experience with a service-provider is not forgotten and can be the difference between accessing a vital service or not.



<sup>7</sup> Cemlyn, S. (2006) Human Rights and Gypsies and Travellers. An exploration of the application of a human rights perspective to social work with a minority community in Britain. *British Journal of Social Work*, pp. 1-21.





## Families often reported that they felt like they were being blamed for causing their own problems



- ❖ There is an incredibly strong family structure in many of the families we work with, including mutual support systems and an acceptance of caring as part of normal life. For many, caring was very much a shared responsibility, with each member of the family taking turns to contribute to the caring. However, not everyone was able to draw on support from the extended family, and even where family support does exist it does not mean that families would not welcome, or benefit from, external services. In other words, the existence of family support should not be used as an excuse for inaction.
- ❖ Caring situations are complex. Most carers have little or no knowledge of how health and social care staff can organise a package of care for elderly, ill or disabled relatives. Few have been involved with social work, or had, where appropriate, care assessments for the person they care for, let alone an assessment of their own needs. As with other carers, many felt guilty when talking about themselves and their day-to-day caring related struggles.
- ❖ The physical health of many carers is visibly bad, and nearly all reported mental health concerns relating to their caring role, including the stress of caring and other issues such as financial struggles, discrimination, isolation and much more.
- ❖ Many mentioned the pressure to keep their identity as a Gypsy/Traveller hidden for fear of being treated differently by services and others mentioned the perceived inability of GPs and service providers to understand the impact of this on mental health.
- ❖ High levels of illiteracy impact significantly on a carer's ability to search for support e.g. using the internet, the phone or written correspondence. Hence, many find it exceptionally stressful and complicated to navigate the referral pathways through community care and social work services.
- ❖ Community care services are often ill-suited to the cohesive and private nature of the Gypsy/Traveller community, and hence Gypsy/Traveller preferences for carers to be within the family/community. This can dissuade carers from accessing Carer Centre or local authority support.
- ❖ None of the carers we work with are currently accessing any of the Self Directed Support options. One person thought she might have heard about it in the past but when she had asked her Social Worker she'd been told *"it wouldn't be appropriate and just more hassle than it's worth."* We are keen in phase two of the project to explore the possibilities offered by the Scottish Government's Self Directed Support Bill, providing further opportunities for Gypsy/Travellers, and others, to direct their care and support in a culturally appropriate way.

In the face of these multiple challenges and complex care situations, the resilience and determination shown by most Gypsy/Traveller carers is, at times, truly astounding.

## Examples of support to carers:

- ❖ Carer looking after elderly parent, MECOPP supported the carer to acquire aids for the bathroom and appropriate seating. Now assisting them to find out more about Direct Payments.
- ❖ Siblings caring for a brother who has multiple physical and mental health issues who live in a remote area with limited access to a phone. They also support other community members living nearby. With support from MECOPP the brother now receives Disability Living Allowance and his main carer receives Carer's Allowance.
- ❖ Carer caring for a relative with learning disabilities and mental health issues and living in sub-standard accommodation, the carer felt frustrated and not listened to by service-providers. MECOPP assisted the carer to request a multi-agency meeting to discuss matters and supported the carer and 'cared for' to access Independent Advocacy Services. A negotiated move into more suitable accommodation on a local site was agreed but has yet to progress. MECOPP are following up this case.
- ❖ Supported an informal carer to secure employment as a part-time paid carer, assistance with preparing a CV, providing a reference, identifying skills and strengths and emotional support, thereby improving their chances of finding employment.
- ❖ Carer looking after young son with physical health problems, MECOPP supported the carer to secure appropriate welfare benefits, in conjunction with the Welfare Rights team, and advice on dietary requirements.
- ❖ Assisted a carer to secure a Community Care Grant of £1,500 to purchase essential household items to allow a relative to be cared for at home.
- ❖ Carer, caring for elderly parent with dementia, has been supported to contribute to a condition-specific study and resource being developed by Alzheimer Scotland and is now more aware of local dementia services.
- ❖ One young carer was supported through the application and interview process for a local college course. His application was successful.
- ❖ Family with two disabled children have been supported regularly in completing forms and with phonecalls to various agencies. By providing 'a listening ear' the family have been able to express their sadness at being forced to live in a house and the consequent loss of culture, as well as practical support from the extended family. Working with an older sibling in recognising their role as a Young Carer and hoping to access funding for driving lessons. Also working towards literacy support to build self-confidence in achieving their aspiration to run their own gardening business.
- ❖ Supporting two carers to access local voluntary sector mental health services.
- ❖ Working with a young mother who has three caring roles for an older relative, a sibling and her partner. MECOPP has provided support to secure more appropriate accommodation, with form-filling and accessing an occupational therapy assessment.
- ❖ Assisting an elderly carer, looking after husband with dementia, to access appropriate welfare benefits (over £300 per week) and Warm Home Discount.
- ❖ Family with disabled child have been able to access flexible respite, for the first time in twenty years, to support a much-needed family break, including the disabled child. A laptop has also been accessed and the family have been supported in organising broadband access. This allows different generations of the family to have improved communication, access to services and information.
- ❖ Carer now regularly attends the local Carer Centre, attends cooking classes and is developing relationships with staff and other carers at the centre. Carer being supported to research life as a Gypsy/Traveller and the impact the caring role has had on life.



# Awareness-raising Training

From the outset, we were very aware that amongst service-providers, and the general public, there is much ignorance and misunderstanding about Gypsy/Travellers living in Scotland. Gypsy/Travellers are rarely mentioned, if at all, in diversity or cultural competency training. Despite legal recognition, as a community, they are often not even regarded as a Minority Ethnic community and remain excluded from many initiatives targeted at Black and Minority Ethnic (BME) communities.

With this in mind, building on the good practice developed by Gypsy/Travellers and previous projects,<sup>8</sup> MECOPP initiated a programme of awareness-raising training for service-providers. Each session used a range of participatory training materials which have been designed and developed by Gypsy/Travellers and support agencies. In each of the three localities, a small team of Gypsy/Traveller trainers were recruited, trained and supported to lead and deliver each training session.

The aims of the awareness-raising sessions were to:

- ❖ improve understanding of the situation of Gypsy/Travellers carers in Scotland
- ❖ highlight the discrimination faced by Gypsy/Travellers
- ❖ increase knowledge of the policy and legal framework in Scotland
- ❖ reflect on our own attitudes, assumptions and actions

In total we delivered eight sessions to 116 service-providers. Each session was evaluated using an anonymous feedback form. In brief, the feedback was overwhelmingly positive – *“I enjoyed the whole event and the interaction with the Gypsy/Traveller Trainers, however, I found the free-flowing discussion flowing from some of the scenario exercises best,”* and, *“The seminar was all very useful specifically because there was plenty of time for questions, discussions, and testimonials. Also, the case studies allowed for topics to come up that might not have been brought up otherwise.”*

<sup>8</sup> For example, Save the Children (Scotland) and Equality, Diversity and Inclusion Services Ltd

## Participant evaluation:

111 participants completed an Evaluation Form at the end of the session, a response rate of 96%. The feedback was extremely positive with most participants finding the seminar useful and informative.

As the following quotes illustrate, by far the most popular part of the seminar was simply speaking directly to Gypsy/Travellers:

**“I found all the seminar very useful. Reading the case studies highlighted to me the various problems/issues that Gypsy/Traveller carers face. The DVD was also extremely useful in hearing peoples own experiences.”**

**“Direct contact with those in the travelling community, helps to put things into perspective. Case studies and subsequent discussions help make us aware of all agencies that can be accessed. Definitely raised awareness of barriers facing Travellers.”**

**“All the parts were excellent, great to hear people’s experience and be able to have time to swap ideas and thoughts. The trainers were excellent.”**

**“I enjoyed the whole morning – a mix of listening and interacting. Meeting and working with real “Travellers” was especially good – listening to their thoughts and ideas.”**

**“Case studies and hearing real life studies. Meeting ‘real’ people is worth more than any amount of reading, TV etc.”**

**“Best was meeting and talking with Travellers and learning from them. The session was well structured to allow for open discussion and plenty space to explore ideas.”**



## Gypsy/Traveller trainer evaluation:

An independent evaluation was carried out with 10 of the 11 trainers in February 2012. All the trainers said they had enjoyed the experience and learned something new – describing it as *“very useful”, “100% positive”* and *“encouraging ... something capable of enlightening your mind, your views”, “very helpful, not only for the people we have been delivering the training to, but we as Travellers took a lot out of it as well.”* Most referred their experience as *“very fulfilling”* because *“...you get your point across, you realise that you can change other people’s mentalities.”*

The trainers also said they had acquired knowledge about their rights and made professional contacts that helped them in the future *“now I know who I should contact when I need something and I can pass the information to other people in my family and in my community.”* They also said they had become more aware of statutory obligations towards Gypsy/Travellers, *“This experience educated me. I had a chance to get in contact with a lot of different organisations.”* Although another trainer added *“The training sessions are good to improve understanding amongst those who deliver the services about what the barriers are, but it’s the people who take the decisions that need to see these barriers really. There need to be people further up, the Councillors, the MSPs.”*

Another recurrent theme was that by being involved, the trainers had increased their confidence, as one commented: *“I used to be much more shy, I used to keep things locked up, while now I feel I want to speak my mind. I don’t want to keep things locked up anymore.”* Another trainer expressed the hope that service-providers would *“start to see the person behind the wheelchair ... now I can see that before I leave this planet things can change for my people.”*

**“I would like to keep delivering these training sessions. Because even if you can change just one person’s mind, it’s a lot better than not changing anyone’s mind.”**





# Social Care Services

One of our key outcomes was to work with statutory and voluntary sector partners to develop their capacity to respond more appropriately to the needs of Gypsy/Traveller carers. It is interesting to note that during initial conversations with health and social care services to promote the project, most said they had had no contact with the Gypsy/Traveller community and were usually unaware of local sites. Most of those we contacted during the first year of the project were positive about meeting, and the aims of project generally, although some remarked that addressing the needs of Gypsy/Traveller carers would be an 'additional' piece of work.

Similarly, at a carer's conference a local councillor commented *"funny, you only read negative things about Travellers, I never actually thought about there being carers or disabled people too."* At the same conference one of MECOPP's staff asked a fellow stall-holder, for a social care agency, if they had ever worked with Gypsy/Travellers before the response was *"oh yes, and from what I've heard we've probably worked with the most notorious ones."*

Of more concern was that several staff, including some at senior level, demonstrated disturbing levels of prejudice and stereotyping towards the Gypsy/Traveller community, and poor levels of impartiality and professionalism when considering individual family issues or circumstances. Staff came across numerous examples where there was no regard for confidentiality when discussing local Gypsy/Travellers. Worryingly, as one MECOPP staff member noted *"some service-providers have shared personal and sensitive information about families in a way which I have not witnessed with other carer families."*

Similarly, social care staff sometimes indicated they were anxious or wary of visiting sites alone, often due to hearsay or gossip. When they did visit sites they sometimes seemed somewhat insensitive, as another staff member noted *"I recently attended, in a supportive role, a meeting in the caravan of a Gypsy/Traveller carer living on a local site. It seemed to be forgotten that this was someone's home. There were four council officials, with different agendas according to the funding stream/department they represented, and it was a challenging experience and very intimidating experience for me let alone the carer."*



Furthermore, some service-providers regularly treated the community as one, rather than as individual families. Similarly, there appears to be limited understanding of the wide range of accommodation options used by Gypsy/Travellers and there is often solely a focus on the 'official' site. Those living in housing, often because of their caring role, are rarely targeted for services or even recognised as being part of the Gypsy/Traveller community.

There is frequently limited understanding of the cultural specificities of the Gypsy/Traveller community, for example the 'network model' of multiple relatives caring for one person or gender issues. Carer entitlements or payment systems – e.g. Carer's Allowance, Direct Payments or respite – do not cater for this model of care.

Staff also observed that the quality of services doesn't seem to be as closely monitored as they could be, nor are services necessarily followed up effectively. There is often a sense of *"we've given you a little and you should be grateful for that"* but very often the service or equipment provided only partially meets the needs of the individual/family. Often the onus is put onto the carer to follow up, even though they may not have fully understood what is available or how to

access it. Similarly, assumptions are made about the carers' abilities, and there is a lack of awareness of the difficulties having limited literacy may make, or a lack of confidence in dealing with 'officials'. Such issues are often ignored or missed and this presents great challenges for carers wishing to navigate the system or apply for assistance relating to their caring role. Comments have included:

**“Mrs X (Gypsy/Traveller) knows what help is out there and can phone me whenever she wants.”**

**“I did a care assessment of Mrs Y's mother, but she never followed up.”**

**“they (those on the site) know where I am and how to contact me.”**

**“the site manager phones me if anyone needs my service.”**

Our experience to date suggests there is limited appreciation of the importance of building up trust, or the need for an outreach approach, and sometimes there is an over-reliance on 'gate-keepers'.

Whilst it is undoubtedly true that there is a long way to go, it is also true that there are a handful of staff who are dedicated, positive and making a real difference to the lives of the Gypsy/Travellers they work to support. But these individuals often seem to be working in isolation and lack support from within their own organisations.





# Community engagement

## Outreach

Gypsy/Travellers are often regarded as a 'hard to engage' community. In contrast, we experienced no difficulties in reaching Gypsy/Travellers. By using an outreach approach, essentially going to where people are, we have directly supported over 60 carers within the Gypsy/Traveller community. Outreach has proven to be a highly effective method of community engagement.

It is often forgotten that Gypsy/Travellers meet their accommodation needs in a variety of ways – living in caravans (on local authority/RSL<sup>9</sup> sites, private sites and roadside camps) and in houses (owner-occupied, social housing or private rental). We did not restrict our work to sites, being very aware that many Gypsy/Traveller families have felt forced to move into housing because of their health status and/or caring responsibilities. Contrary to the assumptions made by some service-providers, such families remain very much part of the Gypsy/Traveller community and it is important to note their accommodation needs may well change over time.

## Trust

Not only have Gypsy/Travellers faced centuries of inequalities but also a plethora of short-term projects, many with good intentions but most with limited funding. Not surprisingly this has resulted in frustration and suspicion amongst many community members. As one woman said *"... with country folk [non-Travellers] it is hard, you need to know a person, trust them like, know they'll treat you normal like, I can't explain that feeling when you think they might know who you are. It is like a churning inside, you see it in their eyes even before they say anything"*.<sup>10</sup>

## Events

In addition to visiting people in their own homes we have also organised, with partners, several health and wellbeing events to bring carers together in a safe and informal environment to meet service-providers.

They were also vital opportunities for partner agencies to engage with community members and pass on information about local support services. Most importantly, these events also provided much-needed opportunities for carers to relax, have fun and try out wellbeing activities such as various complementary therapies. Over the last year, with partner organisations, we have organised seven events bringing over ninety Gypsy/Travellers together.

## Using the arts

From the outset, we were aware of the benefits in utilising the creative arts with individuals, some of whom have limited literacy skills, to enable them to express their views and experiences in an enjoyable and empowering way. Recognising the likely reluctance to talk about caring, and the stigma in discussing sensitive issues such as mental health, we used the arts as a means of engaging with individuals and communities at an early stage in the project. Arguably, creativity can be regarded as a pathway in itself which cuts across language, literacy and culture. Some examples of the different ways we used the arts include:

- ❖ Film-making with seven Gypsy/Traveller carers, many speaking for the first time about the issues they face as carers.
- ❖ Poetry by Gypsy/Traveller women and wooden flower-making – displayed during the Moving Minds exhibition at Kelvingrove Museum, part of the Scottish Mental Health Arts and Film Festival 2011.
- ❖ Display of paintings and flower-making at the Perth Gypsy Traveller Get Together, September 2011.

For some it was the first time that they had openly shared their experiences of, and thoughts on, caring, mental health and wellbeing. Further activities, involving Gypsy/Traveller carers and the arts, are being planned for 2012 Scottish Mental Health Arts and Film Festival.

In addition to isolation, the loss of culture is a recurrent theme in discussions with carers, especially those aged over fifty. There is a mourning of lost traditions and values and a tangible fear for the future of the Gypsy/Traveller community. Building on the success of using the arts we will be developing these themes in phase two of the project.

<sup>9</sup> A registered social landlord (RSL) is a housing association or housing cooperative that is registered with Scottish Housing Regulator.

<sup>10</sup> Equally Connected (2011) *Final Report* p26

# Health

There is limited information available in Scotland with regard to the health status of Gypsy/Travellers, but there is increasing evidence from elsewhere that Gypsy/Travellers experience significant health inequalities, high infant mortality rates, premature deaths and higher than average rates of major long-term conditions such as diabetes and cardiovascular disease.<sup>11</sup> In the University of Sheffield matched-subject study, researchers found that overall Gypsy/Travellers reported poorer health status than both white British residents and other minority ethnic groups. In comparison, Gypsy/Travellers were much more likely to have a long-term illness, health problem or disability.

Similarly, a report from Ireland found that mortality rates for Gypsy/Travellers were 3.5 times higher than for the general population.<sup>12</sup> In Scotland, one GP estimated the life expectancy of Gypsy/Travellers was as low as 55 years.<sup>13</sup> A recent report by the Keep Well team in Lothian has confirmed similar findings.<sup>14</sup> Such shocking evidence about health status clearly has significant implications for carers, that is, given the severity of the health problems the potential knock on impact on carers is immense.

In relation to mental health, there is very little published research on Gypsy/Travellers and mental health in the UK. According to Parry's research Gypsy/

Travellers have amongst the highest levels of mental distress in the UK, which results partly from the forced evictions, constant harassment and the physical health problems many individuals face. Similarly, in Scotland the Equally Connected project highlighted that in discussing mental health and wellbeing, two major issues raised by Gypsy/Travellers were the pressures of living in a house and having to hide your identity.<sup>15</sup> The experience of prejudice, or the fear of encountering racism or other types of discrimination, had a significant impact on the lives of the Gypsy/Travellers and a knock on effect on feelings of isolation, help-seeking behaviour, coping strategies and general awareness of existing services. As the Equally Connected report noted *"the Gypsy/Traveller interviewees made frequent reference to racism, or the fear of being treated differently, often shaping their lives in such ways as to avoid situations that might place them at risk. Similarly, interviewees often made reference to hiding their identity in case it placed them in danger, for some it had almost become a way of life. As one woman who attended a Health Fayre said 'you grow up knowing to keep who you are to yourself it is just safer that way, I know it isn't right but I tell the kids that too'."*<sup>16</sup>

<sup>11</sup> Parry, G., Van Cleemput, P., Peters, J., Moore, J., Walters, S., Thomas, K. and Cooper, C. (2004). *The Health Status of Gypsies & Travellers in England*, The University of Sheffield.

<sup>12</sup> University College Dublin (2010). *All Ireland Traveller Health Study; Summary of Findings*, Dublin: University College Dublin

<sup>13</sup> Evidence given to the Scottish Parliament Equal Opportunities Committee, 2001

<sup>14</sup> Lambie, J. (2010) *Report of Keep Well Gypsy and Traveller Outreach Service*, NHS Lothian

<sup>15</sup> Equally Connected (2011), *Final Report*, p47

<sup>16</sup> *Ibid*, p26

## Concluding remarks

This short paper has thrown a spotlight on some of the inequalities faced by Gypsy/Traveller carers in Scotland today. Furthermore, it has highlighted the extent to which many of their experiences remain invisible and largely ignored by the social care agenda.

To request a copy of the DVD, to arrange an awareness-raising training session or for further

information about any of the issues raised in this paper, please contact:

**Michelle Lloyd, Project Manager,**  
**MECOPP, 172 Leith Walk,**  
**Edinburgh EH6 5EA**

**0131 467 2994**

**[michelle@mecopp.org.uk](mailto:michelle@mecopp.org.uk)**

**[www.mecopp.org.uk](http://www.mecopp.org.uk)**



## Acknowledgements

Special thanks are due to the Gypsy/Traveller carers who so keenly shared their views and experiences. Their kindness, courage and tenacity are commendable. Thanks are also due to Morag MacLean, Linzi Ferguson, Lizzie Sosenko, Alawiyyah Abdulrahman, Martina Coccia, Suzanne Munday, Peter Ross, Ruth Moody, David McPhee and Linda Irvine. We are also grateful for the support of our funders, the Scottish Government and NHS Lothian.