



The Scottish Parliament
Pàrlamaid na h-Alba

Equal Opportunities Committee
3rd Report, 2012 (Session 4)
Gypsy/Travellers and Care

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The Scottish Parliament
Pàrlamaid na h-Alba

Equal Opportunities Committee

Remit and membership

Remit:

1. The remit of the Equal Opportunities Committee is to consider and report on matters relating to equal opportunities and upon the observance of equal opportunities within the Parliament.

2. In these Rules, “equal opportunities” includes the prevention, elimination or regulation of discrimination between persons on grounds of sex or marital status, on racial grounds or on grounds of disability, age, sexual orientation, language or social origin or of other personal attributes, including beliefs or opinions such as religious beliefs or political opinions.”

(Standing Orders of the Scottish Parliament, Rule 6.9)

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3rd Report, 2012 (Session 4)

Gypsy/Travellers and Care

The Committee reports to the Parliament as follows—

BUSTING THE MYTHS

1. Before we come to our inquiry's remit, we begin our report as we began the work leading to it: with profoundly shocking truths. In January 2012, we met Gypsy/Travellers who, in partnership with MECOPP, a voluntary organisation working with black and ethnic minority carers of people, led an awareness-raising session. They started with a 'myth-busting' quiz, which we expected to be a light-hearted opener. But we were appalled by what we learnt—

Population unquantified

2. The Scottish Gypsy/Traveller population's size is unknown. The Scottish Government's biannual count estimated the population in 2009 at 1590, but did not include Gypsy/Travellers living in houses for all or part of the year, nor those on roadside camps or on private sites. The Gypsy/Traveller trainers estimated actual numbers to be over 15,000¹. The 2011 census was the first to include Gypsy/Travellers as a distinct ethnic group. Gypsy/Travellers' ethnicity is protected by the Equality Act 2010.

No obligation to provide sites

3. Local authorities are under no legal duty to provide caravan sites for Gypsy/Travellers. From 1980 to 1998, centralised Scottish Office funding was available, which included provision for the issue of site design and management criteria.

Substandard services

4. Over 50% of Gypsy/Travellers will have spent at least part of their lives without access to running water.

Poor quality sites

5. Most council sites for Gypsy/Travellers in Scotland are built in undesirable and unsafe locations, such as beside landfill sites and rubbish dumps, canals, or

¹ Scottish Traveller Education Project, *Lifestyles* ©STEP2012. Available at: http://www.education.ed.ac.uk/step/travelling_communities.php [Accessed 20 September 2012]

railway lines and under electricity pylons. The land used is generally on unpopular 'brown field' sites unsuitable for conventional residential or commercial use.

Uncertainty of GP service provision

6. GP surgeries are able to refuse people as patients without giving a reason; this often happens to Gypsy/Travellers. Sometimes, reasons are given – such as the applicant living on a site that straddles two practice catchment areas or not being able to prove when registering that they will remain in the area for long enough. Many Gypsy/Traveller families regularly travel 200-300 miles to see a GP or dentist whom they trust and know will see them.

Shockingly low life expectancy

7. Scottish Gypsy/Travellers' life expectancy is unknown, although one of our witnesses' own research put it as low as 55 for men. In Ireland, life expectancy for Gypsy/Traveller men is 15 years lower than men in the general population. For women, it's 11 years lower².

Persistent bullying and prejudice

8. According to a Scottish study³, 92% of young Gypsy/Travellers – as young as 7 years old – said that they had been bullied because of their ethnic identity.

9. In the Scottish Social Attitudes survey 2010⁴, 67% of respondents said that they would be unhappy if a close relative married or formed a long-term relationship with a Gypsy/Traveller. By comparison, only 9% said they would be unhappy if a close relative married a black or Asian person. Nearly a quarter said they thought Gypsy/Travellers were unsuitable people to be primary school teachers. Those figures only reflect the views of those willing to admit their true opinions: actual figures for people holding such views may in fact be higher.

Unique lifestyle and culture

10. Gypsy/Travellers do not necessarily live in caravans – as they belong to a distinct ethnic group, they still belong to that group if they live in a house, even if they have never travelled. A university health study⁵ showed that Gypsy/Travellers who suffered the poorest health were those living in houses.

11. The term 'Gypsy/Traveller' refers to a number of smaller ethnic groups and communities, including Scottish Travellers, Irish Travellers, Welsh Travellers and Romanies. Although some customs and beliefs are shared between these groups, all are different. Occupational and 'new age' travellers are different from Gypsy/Travellers and are not considered to be part of a distinct ethnic group.

² University College Dublin (2010), *All Ireland Traveller Health Study - Our Geels*. Available at: http://www.dohc.ie/publications/aiths2010/TR1/AITHS2010_TechnicalReport1_LR_All.pdf?direct=1 [Accessed 20 September 2012]

³ Save the Children Scotland (2005), *Having our Say*. Findings available at: <http://www.gypsy-traveller.org/your-family/young-people/educational-reports-and-resources> (Accessed 20 September 2012)

⁴ Scottish Centre for Social Research (2010), *Scottish Social Attitudes Survey 2010*. Available at: <http://www.scotland.gov.uk/Resource/Doc/355763/0120175.pdf> [Accessed 20 September 2012]

⁵ MECOPP. (2012) *Hidden Carers, Unheard Voices*. Available at: http://www.mecopp.org.uk/files/documents/annual_reports/hidden_carers_unheard_voices_report.pdf [Accessed 20 September 2012].

12. “Gypo”, “Tink” and “Tinker” are all derogatory and racist.

13. Many Gypsy/Travellers speak Cant, a language that has its roots in Sanskrit. Gypsy/Traveller children may be told that they must not speak Cant in school.

PREVIOUS COMMITTEE INQUIRIES

14. In 2001, the Session 1 Equal Opportunities Committee (“the Session 1 EOC”) carried out an inquiry on Gypsy/Travellers and public sector policies⁶. The recommendations in its report (“the 2001 Report”) covered—

- Accommodation
- Health
- Education
- Personal social services
- Policing and criminal justice
- Promoting good relations

15. In 2005, the Session 2 Equal Opportunities Committee (“the Session 2 EOC”) took evidence from Gypsy/Travellers, service providers and the Scottish Executive on how the 2001 Report’s recommendations had been taken forward. In evidence, the Deputy Minister for Communities announced a short-life strategic group on Gypsy/Travellers. The Session 2 EOC agreed to await that group’s outcomes and published *Preliminary Findings on Gypsy/Travellers – Review of Progress*. In 2007, the Minister for Communities wrote explaining that the National Strategy and Action Plan on Race Equality, incorporating the strategic group’s findings on Gypsy/Travellers, would be postponed until the next parliamentary session. The Session 2 EOC did not, therefore, produce a final report on its progress review.

16. The Scottish Government’s Race Equality Statement 2008-11⁷ included a focus on Gypsy/Travellers in the context of promoting race equality and good relations. It stated—

“By March 2011, we expect the education strategy to be in place and in the initial stages of implementation, with young G/Ts having had an input into its development; a number of transit sites to be operational, 2-3 local representative networks to be established.”

17. Our Session 3 predecessors took evidence on the Race Equality Statement in March 2009⁸ from the Minister for Housing and Communities, who highlighted the above plans and funding allocations. However, as of September 2012, the education strategy has yet to be published and we heard evidence to suggest that planned transit sites were not yet operational. One positive outcome was the allocation of £125,500 over two years to the voluntary organisation Article 12 in

⁶ Scottish Parliament Equal Opportunities Committee. 1st Report, 2001 (Session 1). *Inquiry into Gypsy Travellers and Public Sector Policies: Volume 1* (SP Paper 356).

⁷ Scottish Government. (2008) *Race Equality Statement 2008-11*. Available at: <http://www.scotland.gov.uk/Topics/People/Equality/18934/RaceEqualityStatement> [Accessed 20 September 2012].

⁸ Scottish Parliament Equal Opportunities Committee, *Official Report, 24 March 2009*, Cols 906-932.

Scotland to work with young Gypsies/Travellers in developing their skills, opening up opportunities and improving outcomes.

18. In September 2011, 10 years since the 2001 Report was published, we agreed to review progress against that report's recommendations. We started with an awareness-raising session led by Gypsy/Travellers and facilitated by MECOPP.

19. Two clear messages came across during the awareness-raising session—

- Carers in the Gypsy/Traveller community faced great challenges in accessing support services and living with the responsibility of care.
- Accommodation was at the root of many issues faced by Gypsy/Travellers and improvements to where Gypsy/Travellers live could significantly improve their lives.

20. We are frustrated by the fact that, despite various reports and initiatives since devolution – which themselves followed on from previous initiatives under the Scottish Office – very little has been achieved to improve the lives of Gypsy/Travellers. In fact, Gypsy/Travellers still face many of the same problems that have troubled them for decades.

21. We decided to hold an inquiry looking into Gypsy/Travellers and care. The Session 3 EOC carried out work looking into carers' issues, and recognised that further work was necessary on minority ethnic carers. The Scottish Government's 2010 strategy, *Caring Together: The Carers Strategy for Scotland 2010 – 2015*⁹, acknowledged that little was known about certain groups of carers, such as Gypsy/Travellers. Given the wealth of information available through MECOPP's work, we decided to launch the inquiry at the oral evidence stage.

22. As well as the inquiry into Gypsy/Travellers and Care, the awareness-raising session led to two other workstrands—

- to raise the profile of the awareness-raising work, we sponsored an event in the Parliament launching MECOPP's report, *Hidden Carers, Unheard Voices*¹⁰, in March 2012.
- we agreed to launch a second inquiry, looking into accommodation issues. We launched a call for written evidence on *Where Gypsy/Travellers Live* in March 2012 and expect to report our findings in early 2013. The two inquiries will naturally overlap: this report takes into account some issues related to accommodation. Similarly, we shall take the Gypsy/Travellers and Care evidence into consideration during the *Where Gypsy/Travellers Live* inquiry.

⁹ Scottish Government. (2010) *Caring Together: The Carers Strategy for Scotland 2010-2015*. Available at: <http://www.scotland.gov.uk/Publications/2010/07/23153304/2> [Accessed 20 September 2012].

¹⁰ MECOPP. (2012) *Hidden Carers, Unheard Voices*. Available at: http://www.mecopp.org.uk/files/documents/annual_reports/hidden_carers_unheard_voices_report.pdf [Accessed 20 September 2012].

23. One of the strongest messages that came across throughout our inquiry is the importance of trust. Gypsy/Travellers must be able to place trust in individuals providing support services, and there are many ways in which trust can be gained or lost. This should be kept in mind whilst reading this report.

ACCESSING CARE SUPPORT

Background

24. We heard that, in most care situations, the GP who either diagnoses a condition or makes a referral will be the first point of contact for both carers and cared-for people. Examples of good practice in supporting carers came largely from engagement with Gypsy/Travellers at a general healthcare level. Models presented within evidence suggest 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.

Accessing health and care services, including outreach

Awareness of support options

25. Gypsy/Travellers¹¹ and healthcare workers¹² alike spoke of Gypsy/Travellers' poor understanding of support available to them. We heard that treatment was often sought at the last minute and that there is a lack of both preventative and on-going treatment. Dr Iain McNicol, a retired GP with over 30 years of experience of working with Gypsy/Travellers at his former practice in Port Appin, spoke of Gypsy/Travellers' relying on accident and emergency units or GPs' out-of-hours services, forcing a reactive approach to health care, by which the immediate problem might be treated, but the root causes left un-investigated¹³. He added that the reduction in GPs surgeries offering an out-of-hours service could have a negative impact on the number of Gypsy/Travellers visiting GPs¹⁴.

GP services

26. We heard that Gypsy/Travellers may travel hundreds of miles to see a trusted GP or midwife¹⁵. Both healthcare visitors and GPs spoke of instances where they had been able to build trust amongst Gypsy/Travellers and explained that continuity of care had led to Gypsy/Travellers visiting GPs more frequently, opening up more, learning more about preventing ill-health and bringing family members in for care¹⁶. Both Joan Watson (West Lothian Community Care and Health Partnership) and James Lambie (NHS Lothian) highlighted the benefits of healthcare professionals being willing to offer support outside of their professional role, for instance by helping a Gypsy/Traveller patient to fill out a passport

¹¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 405-406

¹² Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 442.

¹³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 442-443.

¹⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 446.

¹⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 440 and 443.

¹⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 441-442.

application form¹⁷. The potential use of Gypsy/Traveller peer ‘advocates’ to encourage a healthy lifestyle was also suggested¹⁸.

27. We heard of cases where GP surgeries had refused to register Gypsy/Travellers—some surgeries may refuse a patient on the grounds that they have no fixed address, they do not have photographic ID, they cannot guarantee that they will stay in the area for 3 months or more, or the address of their permanent site falls on the boundary between two local authorities (this applies to two council-run sites, Old Dalkeith Colliery and Tealing). We were also told of surgeries that would refuse to register Gypsy/Traveller patients after having difficulties with previous Gypsy/Traveller patients missing appointments.¹⁹

Health initiatives

28. Dr Iain McNicol described a multi-agency health initiative in Argyll, which included working together with Gypsy/Travellers on awareness-raising and education events and activities, such as using CO² or blood pressure monitors and giving smoking cessation advice at ‘family days’. As a result of such initiatives, relationships between Gypsy/Travellers and the non-Traveller community in the area had improved on the whole, with a greater cultural awareness and acceptance of each other’s lifestyles. He also noted that his own research showed an increase of six years, from 55 to 61, of the average life expectancy of male Gypsy/Travellers over a 12 year period.²⁰

Barriers to engagement

29. Centralisation of services and the reduced role of GPs (for instance, changes to out-of-hours contracts) were seen as barriers to engagement. Dr McNicol gave an example using midwifery services:

“Unfortunately, due to the way in which midwifery services in Scotland have changed, GPs now have very little to do with midwifery. Women now go to midwifery services and, even in the small village where I live, having delivered, over 30 years, more than 300 children in that community, I can see someone walk in with a baby and wonder where they got it from, because they have had a baby on their own, with the services. They have gone to the midwife, but midwives do not think to tell us, although we may see the person with a bump and wonder whether they are pregnant.

That is a very sad reduction in services for young women, and it has repercussions, because that is when one gains the trust of young mothers to look after their children. The immunisation success we had in the 1990s and 2000s was because the mothers trusted us. The immunisation rates in the Traveller population went from zero in 1990 to more than 80 per cent by 2005. I suspect that it will slip back again.”²¹

¹⁷ Scottish Parliament Equal Opportunities Committee, *Official Report, 29 May 2012*, Col 452.

¹⁸ Scottish Parliament Equal Opportunities Committee, *Official Report, 29 May 2012*, Col 445.

¹⁹ Scottish Parliament Equal Opportunities Committee, *Official Report, 29 May 2012*, Cols 443-446.

²⁰ Scottish Parliament Equal Opportunities Committee, *Official Report, 29 May 2012*, Cols 445 and 452-453.

²¹ Scottish Parliament Equal Opportunities Committee, *Official Report, 29 May 2012*, Col 441.

Health visitors

30. Healthcare witnesses gave evidence to support the role of dedicated health visitors visiting both permanent and temporary sites. Where temporary sites had been set up, the local health visitor was informed by the local council or police, and then visited the site to ask whether anyone required treatment or advice. This might include giving children immunisations on-site²². Although this approach has worked well, it does not address the issue of discrepancies in the provision of service between health boards. In order for Gypsy/Travellers who travel to receive consistent care, it is imperative that all NHS health boards take a similar approach.

Scottish Government

31. The Minister for Public Health, Michael Matheson MSP (“the Minister”), spoke of a range of approaches being employed by health boards, including outreach initiatives and health visits to sites, and linking patients directly to GP practices and dentists. He expressed the view that services should be open and accessible to everyone and that good practice in sharing information and improving patient access should be universal²³. He also outlined the Scottish Government’s directive to health boards to continue the mainstreaming of the Keep Well programme, and acknowledged the need to continue to refresh work done with Gypsy/Travellers to ensure initiatives are relevant and up to date, and to establish consistency across health boards through the identification of good and poor practice²⁴.

Conclusion

32. That any individual could be turned away from what should be a free, universal healthcare system was one of the most alarming pieces of evidence we heard. We urge the Minister to report to us, clarifying what obstacles exist, on what steps can be taken to stop the practice of refusing GP treatment and/or registration to Gypsy/Travellers – and, indeed, to anybody who requires it, irrespective of background or housing arrangements.

33. We highly commend the work carried out by individual health care practitioners and voluntary services in developing health awareness initiatives and helping Gypsy/Travellers to understand the support available to them. We recommend that the Scottish Government and the NHS consider further how such initiatives can be repeated and maintained. Such initiatives should not overlook Gypsy/Travellers who travel, or Gypsy/Travellers living in bricks-and-mortar homes. We ask that for this, and all recommendations in this report, the Scottish Government report back to us on progress.

34. Having heard evidence outlining negative effects of centralisation of midwifery services on the relationship of trust between Gypsy/Travellers and GPs, we call on the Scottish Government to review this aspect of Gypsy/Traveller healthcare. We ask the Government to establish a timetable for the review and to inform us of the timetable.

²² Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 441-442.

²³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 594.

²⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 597-598.

Hand-held health records

Development and implementation

35. The Session 1 EOC inquiry led to the roll out of the patient hand-held record²⁵ (HHR). They were originally distributed to health boards by the National Resource Centre for Ethnic Minority Health (NRCEMH). However, NRCEMH no longer exists and has been taken over by the Equalities and Planning Directorate of Health Scotland. The Minister for Public Health confirmed that GP practices were sent sample HHRs and given the opportunity to order as required; approx. 1060 HHRs were ordered, with the largest requests in Greater Glasgow and Clyde, and Lothian. 16 awareness-raising events to support the roll-out were held in 2007 following two pilot sessions in early-2006. NHS Scotland currently has 1290 copies of the HHR in stock, and responsibility for on-going awareness-raising lies with individual health boards. An evaluation of take-up and questionnaire survey for recipients of the HHR were carried out in 2009, however only 9 of 170 questionnaires were returned.²⁶

Consultation with Gypsy/Travellers

36. Gypsy/Traveller witnesses confirmed that over 100 Gypsy/Travellers were involved in the records' development, and their use was up to the individual traveller. Some chose not to use them as they preferred not to give their personal details, but those who did use them found them very effective²⁷. Dr Iain McNicol explained that—

“... people thought that it would give the police the chance to ask them where their medical hand-held record was and who they were. They thought that it would become an ID card, which they were vehemently against.”²⁸

37. Dumfries and Galloway was noted as an area where roll-out had been relatively successful²⁹. In practice, some GPs will accept the use of hand-held records, and others will have no knowledge of them so will not – this difference can even occur between two GPs at the same practice³⁰. One GP witness explained that using the HHR effectively doubles the amount of paperwork to be carried out as standard records still needed to be filled out³¹; this could go some way to explaining the limited take-up. Gypsy/Traveller witnesses stated that moving from standard to hand-held records could cause problems, with one individual being left with essentially no medical records³².

On-going issues

38. Introducing HHRs does not seem to have tackled any underlying discrimination against Gypsy/Travellers accessing practitioner services, despite awareness-raising built in to the roll-out³³. Health and social care witnesses

²⁵ MECOPP, Further supplementary written submission, 18 June 2012, page 2.

²⁶ Minister for Public Health, Written submission, 30 May 2012

²⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 391.

²⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 448.

²⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 394.

³⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 392.

³¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 448.

³² Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 392.

³³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 323.

suggested identifying on popular travelling routes (possibly through a mapping exercise, see paragraph 95) GP practices that would accept Gypsy/Traveller as patients without registration. These 'open-house' practices would share medical records and see Gypsy/Travellers at short notice. Such practices may need additional funding for practical reasons³⁴.

Scottish Government

39. The Minister confirmed that a full review of hand-held records was planned, with the aim of improving the current system and reviewing the general approach to providing health care to Gypsy/Travellers—

“... we have looked at whether we could do more to improve consistency in the use of hand-held patient records, whether there are problems with them that act as barriers so that they are not used in some areas, why there is good practice in one health board area and not in another and what lessons can be learned from that, and we have asked the equality unit in NHS Health Scotland to undertake a stocktake of what each board is doing, how widely each board is using hand-hand records, what the benefits are when boards use them, what the barriers are to those that do not use them, and what we can do to encourage their greater use. NHS Health Scotland has started that work, which will give us a much more thorough and detailed insight into the pros and cons of hand-held records.”³⁵

Conclusion

40. **We welcome NHS Health Scotland's current review of the approach to general health care provision for Gypsy/Travellers, including the hand-held health records. We ask that the review take into account—**

- **This report's recommendations on the provision of general health care, outreach services and support for staff.**
- **Alternative options for support, including the identification and provision of open-house or drop-in surgeries, and/or the development of a network through which GPs can share information regarding patients moving from one local authority to another**

41. **We seek assurance that the review takes into account our concerns that—**

- **hand-held records were presented to health boards as a voluntary option during roll-out – the voluntary element should be aimed at Gypsy/Travellers themselves as opposed to health boards and GP practices;**
- **the requirement for GPs to complete both the hand-held record and the standard medical record means that they might not offer them to new Gypsy/Traveller patients or refuse to accept them; and**

³⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 449.

³⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 592.

- **the awareness-raising planned during roll-out was not employed extensively enough to ensure support and understanding amongst GPs, and a rolling programme of awareness-raising was not planned to take account of staff turnover.**

General health

Common health complaints

42. In its written submission, the Edinburgh Access Practice (EAP) proposed a model of support for Gypsy/Travellers and referred to research carried out as part of EAP's local Keep Well programme for minority groups in Edinburgh and the Lothians. EAP's research found—

“There is increasing evidence that Gypsy/Traveller individuals report poor health status and are very likely to have long-term limiting illness (Parry, Van Cleemput, Peters et al 2007) as well as even poorer health outcomes than other ethnic minorities (Peters, Parry, Van Cleemput et al 2009). Life expectancy mirrors that of a 1940s population (Tan, Avalos, Dineen et al 2009) and has been estimated by a Scottish GP at about 55yrs old.”³⁶

43. The EAP research showed higher-than-average obesity levels, hypertension, risks for diabetes, heavy alcohol use and/or smoking, and risk of cardiovascular disease amongst Gypsy/Travellers compared with the general population. EAP ascribed that to a lack of understanding amongst Gypsy/Travellers about the links between lifestyle and health, and a lack of long-term engagement with healthcare support. Gypsy/Travellers participating in the programme expressed a preference for audio-visual aids in helping to explain health conditions and a desire for a dedicated health service better tailored to their community's needs³⁷.

Causes of ill-health

44. Voluntary sector witnesses gave the impression that not enough is known about the reasons behind the distinct health concerns of Gypsy/Travellers³⁸. For instance, it is not clear whether the apparently rare occurrence of dementia amongst Gypsy/Travellers is because of under-diagnosis (related to lack of engagement with GP services), low life expectancy, or genuinely low levels of the disease³⁹. Suzanne Munday (MECOPP) spoke of Gypsy/Travellers feeling “pathologised because of their lifestyle” and “being blamed for the health problems that they have”.⁴⁰

Living conditions

45. Gypsy/Travellers cited living conditions as a cause of ill-health, with Shamus McPhee describing the isolation and enforced sedentary lifestyle of living on a [council provided] site as being “like living in Château d’If in ‘The Count of Monte

³⁶ Edinburgh Access Practice. Supplementary written submission, page 4.

³⁷ Edinburgh Access Practice, Written submission, page 3, paragraphs 5-6.

³⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012

³⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 334-335.

⁴⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 338.

Cristo”⁴¹. Living conditions on sites and the fight to improve site quality, alongside social stigma and prejudice experienced as a result of site living, are seen as a main cause of both physical and mental health issues. Lizzie Johnstone, a Gypsy/Traveller living in a bricks-and-mortar home wrote a poem especially for her evidence session with us. In it, she described how isolation from her culture and discrimination on the part of both local authorities and local communities had affected her:

“I have written a poem that is not directed to anybody, and I hope that it does not cause offence to anybody, but perhaps it covers some other things to do with how being in a house makes me feel ...

Are you sitting comfortable
Are you listening
Are you awake
Please take notes
I really don't mind

I am a Traveller
I am a mother
I am a full time carer
To my son

It hasn't always been easy
In fact I can say
It's been a nightmare
At times over the years

I have felt frustrated
I have felt isolated
I have felt suffocated
No one taking
Any notice or understanding
How I am feeling
Like an animal trapped in a cage
Screaming to get out

Why can't someone show compassion
And realise I need help
To figure out even my son's medication
As I can't read or write

It's not my fault I am only doing my best
Thought I made the right decision
Moving into a house
Giving up my culture
And ways of life
So my son
Could get the proper health care he was entitled to

⁴¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 395.

Like everyone else

For God's sake
Please don't let other Travellers
Suffer the way I had to."⁴²

Cultural differences

46. Witnesses also spoke of the effect of cultural differences on general health. As well as a lack of general knowledge regarding anatomy and health care (often ascribed to a lack of literacy and limited educational attainment)⁴³, and a 'live-in-the-moment' attitude⁴⁴, gender-based cultural issues were spoken of. For example, a Gypsy/Traveller woman is unlikely to be comfortable discussing certain health issues with a male GP⁴⁵, and it may not be considered suitable to have someone of the opposite sex carrying out personal care for an individual⁴⁶. Some Gypsy/Travellers also explained that they did not feel it was appropriate to discuss mental health issues, and in particular, that they did not believe these issues should be treated using medication⁴⁷.

Scottish Government

47. The Minister stated that, in terms of targeting health inequalities, there was "clearly value in consistent health information transferring from one board to the next"⁴⁸, and that a review of hand-held health records (see paragraphs 42-46) may go some way to establishing consistent care. He also highlighted the effectiveness of the Government's Keep Well programme in tackling health inequalities⁴⁹.

Conclusion

48. **We welcome the Minister's recognition that health information about Gypsy/Travellers must be consistent, wherever they access health services. However, we are concerned about the Edinburgh Access Practice's finding that Gypsy/Travellers' unique health needs are not being met. Without a better understanding of those needs and a culturally sensitive approach to general health, there will be inevitable barriers in providing care.**

49. **We recommend that the Scottish Government and its agencies—**

- **work in conjunction with the Edinburgh Access Practice (EAP) and other outreach services in identifying further areas for research, similar to that already carried out by the EAP, into the specific health needs of Gypsy/Travellers.**
- **work closely with Gypsy/Travellers to—**

⁴² Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col. 407.

⁴³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 334.

⁴⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 444.

⁴⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 395.

⁴⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 411.

⁴⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 408.

⁴⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 592.

⁴⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 597.

- a) better identify the root causes of specific health issues experienced by Gypsy/Travellers;**
- b) identify preventative approaches; and,**
- c) establish areas of treatment that may require specific adjustments for cultural reasons**

50. We are looking further at living conditions in our Where Gypsy/Travellers Live inquiry and would anticipate that the Minister for Public Health will take account of the effect of living conditions on Gypsy/Travellers' health, both physical and mental.

DELIVERY OF SUPPORT

Introduction

51. On the delivery of support, it was clear that Gypsy/Traveller witnesses felt strongly that support should focus on supporting carers rather than supplying external carers or offering respite, which some thought ill-suited to Gypsy/Traveller culture⁵⁰. Given the difficulties in going through the assessment process, a support service with an advocacy role, for instance providing support in applying for adaptations – potentially alongside a cultural drop-in centre or carers' group – was suggested⁵¹. With regard to health and social care integration, witnesses spoke of the value in service users having one point of contact for all services they access as opposed to multiple contacts, in particular in ensuring that there are no gaps in support⁵². Good examples of support were often attributable to one person.⁵³ Witnesses from support services suggested that a contact network allowing them to share information would be useful – for instance, it might help one GP to contact another in a different region to advise of a Gypsy/Traveller family's moving to their area and to explain on-going health concerns⁵⁴.

Assessment

Establishing care

52. Support provision for carers relies initially on identification – carers need to either identify themselves or be identified by a service provider, and carers across all backgrounds share certain difficulties in accessing support. It can take up to six to seven months for a carer's assessment and the establishment of a support programme and some problems with access to services may be exacerbated by, for instance, the mobile nature of some Gypsy/Traveller lifestyles; lack of integration in the community; discrepancies in the level of support available and lack of consistent medical records.⁵⁵

⁵⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 409-410.

⁵¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 426-427.

⁵² Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 343-244.

⁵³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 452.

⁵⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 454.

⁵⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 324-325.

Assessment process

53. The single-shared assessment, which should mitigate some issues, focuses on assessing need rather than on setting a treatment and support plan⁵⁶. This means that, in most cases, when a Gypsy/Traveller moves into a new local authority area, a new plan needs to be established⁵⁷. We heard that in some cases the assessment of need also has to be repeated⁵⁸. Even when an assessment of need can be transferred, the recognised level of need or level of support available may vary – for instance, the number of hours of therapy or respite care offered may be different⁵⁹. Witnesses from voluntary organisations explained that one of the key reasons for the delay in completing assessments was a lack of resources within local authorities, and agreed that having a mechanism whereby one local authority could accept another local authority's assessment, and where a transferable 'log' of care plans (similar to the hand-held health record) could be used, may mitigate some of the difficulties faced by Gypsy/Travellers who travel⁶⁰. The need for repeat assessments is both time consuming and resource intensive. A GP seeing a patient who is new to his or her area must, in most cases, start at the beginning of the assessment process. New relationships with other statutory support providers must also be established with the Gypsy/Traveller; as previously stated, continuity of care is crucial in building trust, which this approach does not allow for⁶¹.

Continuity of care

54. Jack Ryan (Crossroads Caring Scotland) spoke of instances where a delay in contact could lead to a breakdown in relationships. He told us, for instance, that, following discharge from hospital, it usually took a few days for on-going support services to make contact with the patient and/or carer. He explained that such a delay could lead to a break in contact, particularly with Gypsy/Travellers who travel.⁶²

Scottish Government

55. Jean MacLellan, of the Scottish Government's adult care and support division, gave details of the independent living movement in Scotland in reference to the assessment process, aimed at the wider community as opposed to Gypsy/Travellers specifically—

"Work is going on in that area to ensure that portability of care becomes a reality, although that will take some time. For example, it would mean that a Gypsy Traveller moving from area to area could take their care assessment and care package information with them to the next local authority. There would be limitations on that regarding resources and local authorities'

⁵⁶ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 330.

⁵⁷ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 331.

⁵⁸ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 331-332.

⁵⁹ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Cols 331-332.

⁶⁰ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 330.

⁶¹ Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 331.

⁶² Scottish Parliament Equal Opportunities Committee, *Official Report, 27 March 2012*, Col 344.

flexibility, but it is an evolving aspect of good practice in the care rather than the health dimension.”⁶³

Conclusion

56. **Although we acknowledge that an assessment of care needs is required for all cared-for individuals – and can take some time – we believe that the increased difficulties that delays in the process can cause for Gypsy/Travellers who travel must be addressed. That the single-shared assessment, which should be portable, may not apply once a Gypsy/Traveller has moved to a new local authority area is unacceptable. We call on the Minister to establish why that occurs and take steps to address the problem and to provide us with an update on progress towards making portability of care a “reality”⁶⁴.**

57. **Witnesses suggested that fast-tracking of Gypsy/Travellers through the assessment and care plan development process may go some way to resolving the issues noted; we believe that ensuring the portability of single-shared assessments and care plans and consistency of care provision will fulfil this aim, and benefit individuals from all backgrounds when relocating. We acknowledge, however, that in implementing such changes a mechanism for repeat assessment would be required as needs do vary over time.**

Payments

Self-directed support

58. Self-directed support (SDS) and direct payments may allow more flexibility for carers, in particular care portability during summer months. MECOPP raised the possibility of using direct payments to encourage many Gypsy/Travellers’ preferred approach of keeping care within the family—

“As members of the travelling community tend to travel with their family, if the opportunity was there to use direct payments to pay for a family member to provide care and, if that person was travelling along with them, particularly during the summer months, we think that that would be a step forward.”⁶⁵

59. Florence Burke (Princess Royal Trust for Carers) expressed that SDS should not become a prescriptive approach for all Gypsy/Travellers (or indeed, anyone in the general population) – provision should be based on the individual, with information about options available being crucial⁶⁶. Alex Cole-Hamilton (Aberlour Child Care Trust) suggested that the added pressure of budgeting and interviewing contractual support providers can place a great deal of unnecessary stress on carers of profoundly disabled individuals regardless of their background⁶⁷.

⁶³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 595.

⁶⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 595.

⁶⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 327.

⁶⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 328.

⁶⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 328.

Ring-fencing

60. Some witnesses from voluntary services spoke of the impact of the end of ring-fencing of funds for provision for disabled children, and the impact that this has had on the ability of local authorities to provide support in cases where the proposed designation for funds was not necessarily made clear and funds were provided within general grant-aided expenditure.⁶⁸

Scottish Government

61. The Minister explained that, in terms of social care provision, Gypsy/Travellers—

“... should be given the same options as everybody else. Those options are to receive a direct payment, to direct the local authority in relation to who provides their care, or to receive a traditional care package to be provided by the local authority—or to have a combination of all three of those. If the Social Care (Self-directed Support) (Scotland) Bill is passed, it will provide people with that legal right irrespective of whether they are a Gypsy Traveller.”⁶⁹

62. He also confirmed that a working group had been set up to look at portability of care in terms of self-directed support—

“Along with COSLA and others, we are working on portability to ensure that if a Gypsy Traveller who has a self-directed support package moves into another local authority area, they will be able to take that package with them. The same care provider may not be able to provide the service in that local authority area, but that is another matter. It is a difficult technical area because there are different charging policies in different local authority areas, and different services are provided in rural and urban areas.”⁷⁰

Conclusion

63. We welcome the Minister’s comments about the care portability working group. However, we recommend that, if Gypsy/Travellers have not been directly consulted during the course of that group’s work that their views be sought on any actions or initiatives arising from the group’s recommendations. We also recommend that any changes in guidance ensure that individual needs are taken into account and that the approach to self-directed support does not become prescriptive.

64. We note that one of the main roles of voluntary organisations supporting Gypsy/Traveller carers is in helping them to understand what support they are entitled to. We believe that such advice for Gypsy/Travellers should also be built in to the health and social care system, including provision of the advice in an appropriate, accessible format. We ask that the Minister investigate the matter further.

⁶⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 332-333.

⁶⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 609.

⁷⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 610.

65. **We note the view expressed by some witnesses on the removal of ring-fencing of funds having an effect on support available to carers. However, we understand that local authorities and NHS boards still have statutory obligations to children with disabilities and we ask, therefore, for details of and reasons for any unmet need.**

Respite care, therapy, and support for carers

Respite care

66. Voluntary sector witnesses confirmed that opportunities for respite care, especially respite care in the home, may be limited for Gypsy/Travellers who travel, though as with many aspects of support services, this could vary from one local authority to another, and there may be barriers to engaging and providing services in areas where there are no formal sites.⁷¹

Cultural competency

67. Gypsy/Traveller witnesses explained that both therapy and respite care may not take into account cultural sensitivities, such as the need for same-sex practitioners and for the family support to remain available during residential stays.⁷² Gypsy/Traveller witnesses also expressed a preference for casual, face-to-face contact⁷³.

The effect of housing on accessing support

68. As mentioned in paragraph 45, one Gypsy/Traveller carer had moved into a bricks-and-mortar home following her son's diagnosis with severe epilepsy, having found that this was the only way to access the level of health care for her son and support for herself that was needed. She had lived in 11 houses in five different council areas over an 18 year period, moving because the houses were unsuitable for her son's condition, or because of persecution from their neighbours⁷⁴. Voluntary organisations suggested that the only way for a Gypsy/Traveller to receive consistent care, support and an education, is often to cease to travel⁷⁵.

Voluntary organisations

69. Voluntary organisations explained that one of their key roles was in helping carers to understand the options for support (including financial support) available to them, once they had been identified as a carer. Only one organisation, MECOPP, worked specifically with Gypsy/Travellers, and the other care organisations giving evidence agreed that improving their own knowledge of Gypsy/Travellers lifestyles and needs would be beneficial.⁷⁶

⁷¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 338.

⁷² Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 400.

⁷³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 405.

⁷⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 403-404.

⁷⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 325-326.

⁷⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 321-333.

Scottish Government

70. The Minister explained that responsibility for ensuring that care and therapy is ethnically appropriate lies with individual social work departments, and should be based on the needs of their local area.⁷⁷

Conclusion

71. As with the provision of other types of support, we recognise that there are regional discrepancies in the level and type of respite care and therapy available and recommend that a minimum standard of support for carers be established.

72. It was clear that cultural sensitivities might be overlooked when providing care for Gypsy/Travellers. We are concerned that the level of cultural competence displayed when working with other black and ethnic minority groups is not routinely matched by providers when working with Gypsy/Travellers. To this end, we recommend that the Scottish Government take steps to ensure that any gaps in cultural awareness training are addressed.

73. We also recommend that NHS Health Scotland and professional bodies within the health and social work sector ensure that any guidance issued relating to cultural competency covers working with Gypsy/Travellers.

74. We were shocked to hear of Gypsy/Travellers feeling that they had no choice other than to settle in housing away from their own communities to access care services, especially given the subsequent detriment to their own health and well-being. We feel strongly that Gypsy/Travellers should not have to abandon their traditional lifestyle and become cut-off from their culture to be able to, for instance, attend regular hospital appointments or secure appropriate adaptations. We therefore recommend that, in establishing care programmes, practitioners should work in partnership with Gypsy/Travellers to find a model of support that suits their existing lifestyle. We hope that improving portability of care through improvements to self-directed support and the single-shared assessment will support this recommendation.

Aids and adaptations

Securing adaptations

75. Witnesses gave a clear indication that a main issue was securing appropriate adaptations for elderly and/or disabled individuals – the wait for adaptations could be very long and required constant liaison with authorities, with the grant application process differing between caravans/chalets and traditional homes. Examples given included—

⁷⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 324.

- 18 months for a shower⁷⁸
- 11 months for steps (where a ramp would have been more appropriate, with more than 2 years to wait for a lift as a replacement)⁷⁹
- 9 months for a suitable chair; and,
- 5 years for a wheelchair (which resulted in the wheelchair user's not being able to attend school as bus operators deemed her existing wheelchair a liability).⁸⁰

76. Fiona Townsley, in telling her story, gave a disturbing account of her experiences obtaining housing adaptations for her disabled mother, and her subsequent fight for improved living conditions—

“I have lived for most of the last 30 years on Double Dykes caravan site. I am a full-time carer for my mother. I thought that being a carer was all about caring for someone—I did not realise that I was also taking on the role of fighting the council. It all started in 2001 and 2002 when we tried to get a shower for my elderly mother. At that time, we lived in caravans and the bathroom was in the amenity block. I was told that, because it was a caravan site, we did not qualify for grants and that there was no way to fund adaptations for disabled or elderly tenants.

Our doctor was good and helped us by contacting the council on our behalf. After 18 months, we got the shower installed. It felt like the council was putting in the shower to shut us up. In trying to get a shower for my mother, we realised that the conditions that we were living in were very poor.

Over the past 10 years, it has been absolute torture simply trying to get information or details from the council, let alone trying to get the aids and adaptations that my parents are entitled to.

I have written countless letters to the council, councillors, MSPs, the Commission for Racial Equality and the ombudsman. I have also visited the citizens advice bureau many times. I have never given up, but some Travellers have, and have gone into housing. I do not think that we would have got as far as we did without help and support from the CAB. The only way I found that I could get information from the council was through the data protection legislation and freedom of information requests. Often, I was refused information, but when the CAB and others phoned, they would be given the information. I spent an afternoon at the council office writing out a copy of the site licence, because the council said that it was not allowed to photocopy it, yet the CAB was sent a photocopy of the same licence.

Travellers' caravan sites are built to the minimum standard, to be robust and prevent any damage. Communities Scotland's inspection report showed that the facilities were below the recommended standard—well below what was

⁷⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 396.

⁷⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 413.

⁸⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 399.

recommended for housing. Even the office that the caretaker works in is of a higher standard than the places that are provided to tenants.”⁸¹

Effect of securing adaptations on carers

77. Being unable to secure aids and adaptations could have a physical, as well as a mental impact on carers. Mary MacDonald explained that—

“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. It was only in February this year that we got a hoist for her.”⁸²

Carer expertise and occupational therapy

78. Gypsy/Traveller witnesses called for their own expertise to be considered, for instance in designing accessible sites and chalets⁸³. Voluntary sector witnesses agreed that there would be merit in Gypsy/Travellers working with occupational therapists and caravan manufacturers in developing adaptations⁸⁴. Kenneth Leinster (South Ayrshire Council) said—

“... we asked the occupational therapist to make contact with the caravan providers. If we have a large number of off-the-shelf adaptations for mainstream houses, we should be able to provide exactly the same service for people in caravans. To date, we have not done particularly well on that. I have asked my staff to look at that much more closely, to ensure that everyone has the right opportunities and an equal opportunity to access the service. As you said, Gypsy Travellers pay council tax and rent, so they are perfectly entitled to such services.”⁸⁵

Scottish Government

79. The Minister spoke about the Scottish Government’s independent adaptations working group, which was due to report in September 2012 on the guidance on the provision of adaptations by local authorities and health services. The hope that was that with the completed report the Government could revise the guidance issued to local authorities⁸⁶.

Conclusion

80. We were horrified to hear of the various delays experienced by Gypsy/Travellers in securing necessary adaptations. We welcome the establishment of the aids and adaptations working group, and urge the Minister to ensure that its work covers a comparison against the overall average waiting times for aids and adaptations and investigation into extensive delays.

⁸¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 396-397.

⁸² Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 399-400.

⁸³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 413-415.

⁸⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 329.

⁸⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 474.

⁸⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 605.

81. We suggest that the working group take into account the expertise of Gypsy/Travellers and their carers, and consult with them accordingly. To support this, we recommend the establishment of a forum whereby social work professionals, occupational therapists and manufacturers can work with Gypsy/Travellers to develop aids and adaptations better suited to trailers and chalets, as well as trailers and chalets designed with accessibility in mind.

82. The fact that privately owned trailers or chalets situated on sites owned by councils and housing associations fall between two systems of support, private owner grants and council-funded aid, is not acceptable. We recommend that the Scottish Government and COSLA establish clear guidelines on which adaptations fall under each form of funding, and work with social care providers and Gypsy/Traveller liaison officers in ensuring that the appropriate support is available in helping Gypsy/Travellers apply for adaptations. As stated in our other recommendations, there should be an emphasis on ensuring consistency across all local authorities.

AWARENESS-RAISING

Introduction

83. We heard evidence to suggest that raising awareness of Gypsy/Traveller culture and lifestyles amongst both public sector and voluntary sector organisations could have a significant beneficial impact on the provision of care and support. Similarly, there was a great deal of evidence in favour of raising Gypsy/Travellers' own awareness of the support available to them and their understanding of general health. We were encouraged to learn that previous work on such initiatives had led to improved relationships and, in particular, increased levels of trust between Gypsy/Travellers and support workers – we cover these in paragraphs 94 to 98.

Cultural issues

Understanding amongst the general population

84. Witnesses from all backgrounds spoke repeatedly about a lack of understanding of Gypsy/Traveller culture, in particular about the distinct ethnic status of Gypsy/Travellers, within the general population. We were disappointed to hear from MECOPP that one of their staff had been asked to write a letter to a service provider confirming that a carer they were supporting was indeed a Gypsy/Traveller⁸⁷.

Discrimination

85. Witnesses also spoke of instances of both direct racial aggravation and indirect discrimination borne out of negative attitudes. Suzanne Munday (MECOPP) explained that—

“... we were talking with a social worker in one of the areas in which we work about a particular client whom we were supporting. The social worker questioned what we said and remarked, “Oh, but we all know what they're

⁸⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 326.

like. They are notorious for things like that.” That is the level of attitude with which we are dealing in the project.”⁸⁸

Lifestyle

86. As stated, not all Gypsy/Travellers travel, and as a result, care provision aimed at Gypsy/Travellers should take into account their varying living arrangements. Jack Ryan (Crossroads Caring Scotland) spoke of Gypsy/Travellers being viewed by local authorities as a temporary problem, who would “move to someone else’s backyard next month”⁸⁹.

Cultural competency amongst service providers

87. MECOPP spoke of general work on cultural competency when working with all black and ethnic minority groups, such as work with health and social care practitioners in ensuring that the single-shared assessment takes into account issues of cultural competency. They suggested that a lot of good practice in working with other black and ethnic minority groups could be applied when working with Gypsy/Travellers.⁹⁰

Literacy

88. Witnesses from all backgrounds spoke of the difficulties faced by Gypsy/Travellers in accessing services due to limited literacy and educational attainment⁹¹. This means that services advertised in writing may not be obvious to Gypsy/Traveller carers, and Gypsy/Travellers’ existing awareness of medical conditions or models of support may be limited⁹². Form-filling can cause difficulties, with one GP witness explaining that he would always advise practice staff not to assume literacy when asking Gypsy/Traveller patients to complete the registration process⁹³. Lizzie Johnstone explained that—

“For the first few years, it was hard for me even to understand the fancy words that the doctors used, for example, and for me to speak up. I could not read or write, and obviously I felt that I was going to cause more harm to my child, as the doctors told me the dosages to give him to control his seizures but I could not read what was on the bottle.”⁹⁴

Community

89. Gypsy/Travellers are a very tight-knit community and they prefer to keep to themselves in many cases⁹⁵. Gypsy/Traveller witnesses have explained that this is in part due to the negative attitudes and discrimination they have experienced from the non-Gypsy/Traveller community in the past⁹⁶. They often live as part of larger family groups, and care is shared between family members⁹⁷. Lizzie Johnstone told us that being a carer isn’t always seen as a specific role by saying “to me, it

⁸⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 326.

⁸⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 339.

⁹⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 329.

⁹¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 334.

⁹² Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 334.

⁹³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 455.

⁹⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 407-408.

⁹⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 411.

⁹⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 405.

⁹⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 410.

feels strange to say that I am a carer because I am just a mother”⁹⁸. Because Gypsy/Travellers may have a lack of trust in people outside their own community, they generally prefer not to give out personal details⁹⁹, and because of past persecution they are often afraid or embarrassed to ask for help, or even to reveal that they are a Gypsy/Traveller¹⁰⁰.

Scottish Government

90. The Minister confirmed that, in relation to issues surrounding prejudice from professionals aimed at Gypsy/Travellers, the Scottish Government—

“... is more than happy to work with professional bodies to address such issues. We already do that with healthcare staff in a number of areas in the NHS in Scotland.”¹⁰¹

Conclusion

91. We were appalled to hear of discrimination against Gypsy/Travellers amongst support workers and lack of acceptance of the community as a distinct ethnic group. As stated in paragraph 72, the Scottish Government must continue to support awareness-raising and cultural competency initiatives to help combat this.

92. One of the main barriers for Gypsy/Travellers in increasing their own ability to interact with the health and social care system is low levels of literacy and education. We therefore recommend that the Minister for Education and Young People acknowledges this and ensures the inclusion of Gypsy/Travellers in forthcoming outreach and adult learning strategies.

93. The traditional model of care-in-the-family described to us by Gypsy/Travellers is a positive approach which should not be prevented by bureaucracy. As such, we recommend that in reviewing models of support and care provision NHS Health Scotland ensure that enabling shared care be taken into consideration alongside other culturally sensitive approaches.

Models of support and voluntary organisations

MECOPP

94. As stated, we worked with MECOPP throughout our inquiry, and will continue to do so during our ‘Where Gypsy/Travellers Live’ inquiry. Suzanne Munday explained that MECOPP—

“... are the only dedicated minority ethnic carers organisation in Scotland and we specialise in supporting groups that are either historically or by default marginalised from mainstream services. We are managing and delivering the Gypsy Traveller carers project, which is funded by the Scottish Government.”

“The project contains several strands, including the key strand of advocacy support, which involves enabling Gypsy Traveller carers to articulate their

⁹⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 405.

⁹⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 395.

¹⁰⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 408.

¹⁰¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 609.

needs to providers or supporting them in a partnership approach and advocating on their behalf. We have provided a lot of healthy living activities for Gypsy Traveller carers, and offered a range of training opportunities for health and social care practitioners to raise their awareness of Gypsy Traveller issues.”¹⁰²

Mapping travelling patterns and living arrangements

95. Witnesses from voluntary organisations emphasised the importance of recognising that Gypsy/Travellers have varying lifestyles and are not simply a homogeneous group, and suggested mapping Gypsy/Travellers’ lifestyle and travelling patterns to help better understand their needs. An audit of attendance at GP practices geographically close to local authority sites was also suggested¹⁰³. Service providers suggested that having formal transit sites would make it easier for health visitors and carers centres to identify and visit Gypsy/Travellers consistently¹⁰⁴. It was highlighted that the terminology generally used for temporary camps, such as ‘unauthorised’ or ‘roadside’, had negative connotations and that more positive language may help to improve perceptions of Gypsy/Travellers amongst the general public¹⁰⁵.

Site managers and Gypsy/Traveller liaison officers

96. Kenneth Leinster (South Ayrshire Council) explained how the site manager for the area’s only council-run site acted as liaison officer, and was in effect the primary conduit between the council and health and social care services for all Gypsy/Travellers on the site – for instance, they might be the one to contact a health visitor on behalf of residents¹⁰⁶. Opinions from Gypsy/Travellers on site managers and liaison officers varied, with some seeing site managers as potentially effective in advocating on the need for adaptations (though with limited powers)¹⁰⁷, and others wishing to keep support services at “arm’s length”¹⁰⁸. The positive aspects of liaison officers being employed from outwith local authorities, for instance by the Citizens Advice Bureau, were highlighted by Gypsy/Travellers¹⁰⁹.

Voluntary organisations

97. Voluntary organisations agreed that referrals from Gypsy/Traveller liaison officers to their organisations, and/or fast-tracking Gypsy/Travellers through the assessment process, would be beneficial, but would be resource intensive for local authorities and would require changes in practice, and acknowledged that available and recommended care and support differs between local authorities¹¹⁰. Florence Burke explained that the Princess Royal Trust for Carers did not ask

¹⁰² Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 322-323.

¹⁰³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 456.

¹⁰⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 472.

¹⁰⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 472.

¹⁰⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 470-471.

¹⁰⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 426.

¹⁰⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, 429.

¹⁰⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 427.

¹¹⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Cols 326-327.

whether service-users were Gypsy/Travellers, but conceded that doing so could lead to better understanding of the group's specific needs¹¹¹

98. Linda Irvine (NHS Lothian) suggested that a more flexible approach to technology might improve support available to Gypsy/Travellers—

“... it is now 2012 and we should be discussing how to use technology such as texting with mobile phones to improve communication within healthcare and with Gypsy Traveller communities. That cannot be beyond us, given that we are quite a small country. It would be innovative to consider how we could use telehealth initiatives to support some of our work with Gypsy Traveller communities.”¹¹²

Scottish Government

99. The Minister agreed that working with Gypsy/Travellers in establishing their needs was important, and that—

“The idea of mapping out Gypsy Traveller-friendly services has a level of merit. My concern about that approach is that there might not be a uniform pattern of such services across the country, and individuals might not be in close proximity to a particular service.”¹¹³

Conclusion

100. **We recognise the impact that MECOPP has had on the lives of the Gypsy/Travellers it has worked with, and are encouraged to hear that it obtained funding for a further three years in April 2012. One thing that has been clear to us throughout our work with MECOPP is the value of the awareness-raising sessions they run with Gypsy/Traveller trainers, in particular in their ability to dispel common misconceptions and give key support workers the opportunity to meet Gypsy/Travellers and hear their stories. Therefore, we recommend that the Scottish Government support the continuation and expansion of MECOPP's exemplary work when funding is due for renewal in 2015.**

101. **We also recommend that other voluntary sector organisations draw on MECOPP's work with the aim of developing a network of expertise able to support both Gypsy/Travellers and health and social care workers across Scotland. This should include exploring alternative approaches to support such as telehealth models.**

102. **It is clear to us that one of the greatest barriers to supporting Gypsy/Travellers who travel is a lack of understanding about their lifestyle, population and travelling patterns. This means that the bi-annual count of Gypsy/Travellers carried out by the Scottish Government is unlikely to give an accurate picture of the population. We recommend that the Scottish Government commission a mapping exercise, as soon as is practicable and taking into account information from the 2011 census (which may itself not**

¹¹¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 340.

¹¹² Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 457.

¹¹³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 599.

accurately reflect the size of the Gypsy/Traveller population), to better establish actual numbers of Gypsy/Travellers, popular travelling routes and population centres. We hope that such an exercise will help in establishing locations where—

- a) increased training and support for key workers will be beneficial
- b) new outreach services, community groups and health initiatives can be set up
- c) additional permanent pitches/sites or temporary stopping places may be needed

103. Although we heard differing views on the ‘ideal’ role of Gypsy/Traveller liaison officers (GTLOs), it is clear that in some cases these individuals have provided a great deal of support to Gypsy/Traveller carers in accessing health care services. We therefore recommend that all 32 local authorities review the role of GTLOs in partnership with Gypsy/Travellers to ensure consistency of support across Scotland. It should be borne in mind that in some cases a reduced level of interaction may be at the behest of local Gypsy/Travellers, however that this should not mean a higher level of support is not available to those who need or want it.

STRATEGIC LEADERSHIP

Introduction

104. Poor progress on the 2001 inquiry recommendations has been ascribed to a lack of strategic leadership and a lack of connection between Gypsy/Travellers and elected representatives. Fiona Townsley raised the point that local authorities have not planned for growth of the Gypsy/Traveller population¹¹⁴. Monitoring of any initiatives and policies was deemed of vital importance.

Funding

105. Funding was raised as being at the heart of many issues. Gypsy/Traveller witnesses spoke of instances where they had been told that there would be a finite number of site upgrades due to limited funding. Gypsy/Travellers from different sites were put in the position of having to ‘bid’ for funds, present cases and compete for site improvements and adaptations needed by elderly and/or disabled residents¹¹⁵. We heard of positive examples of engagement and outreach programmes which had ceased to operate as a result of funding being withdrawn¹¹⁶. Gypsy/Travellers expressed a lack of confidence in new initiatives as they had been involved in so many that have had a limited life-span in the past¹¹⁷.

¹¹⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Col 398.

¹¹⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 415-416.

¹¹⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 453.

¹¹⁷ Scottish Parliament Equal Opportunities Committee, *Official Report*, 15 May 2012, Cols 405-406 and 422

Strategic support for key staff

106. As stated, many examples of good practice are ascribed to one individual, and we heard about instances where such individuals had to overcome policy-based barriers and work outwith their remits, and potentially with little strategic backing, to provide support¹¹⁸.

Cultural competency

107. A lack of cultural awareness at a strategic level was seen as a root cause of many of the issues faced by Gypsy/Travellers when accessing support services. Health and social care witnesses spoke of positive practice-wide initiatives, facilitated and led at a strategic level, such as inviting Gypsy/Travellers into the practice to discuss what model of health care would best suit them¹¹⁹, providing awareness-training for staff¹²⁰, and ensuring that staff members are aware that any discriminatory behaviour towards Gypsy/Travellers would be classed as gross misconduct¹²¹. A lack of knowledge about how local authorities could support Gypsy/Travellers in accessing their services was seen as a barrier to providing support¹²².

Terminology

108. The use of negative language was raised as one barrier to addressing negative attitudes towards Gypsy/Travellers, in particular the use of terms such as 'unauthorised encampments' in official documentation. A positive change in attitudes to Gypsy/Travellers following the 2001 report, which included the recommendation that public bodies universally use the term 'Gypsy/Traveller', suggests that further establishing which terms Gypsy/Travellers find appropriate may be beneficial.¹²³

Scottish Government

109. The Minister emphasised that the Scottish Government's favoured approach to strategic leadership was through mainstreaming the provision of care—

"We have tried to ensure that we mainstream the provision of care, because we believe that anyone, irrespective of their background, ethnicity or place of residence should be able to access healthcare services. That is probably a better approach to the provision of health services in Scotland."¹²⁴

and that—

"We are always looking within NHS Scotland to see how we can improve patient access to the health service in general. Some of that is around information sharing between different health professionals or between social care and health professionals. We will always consider and try to encourage

¹¹⁸ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Cols 450-451.

¹¹⁹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 467.

¹²⁰ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 477-478.

¹²¹ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 455.

¹²² Scottish Parliament Equal Opportunities Committee, *Official Report*, 27 March 2012, Col 339.

¹²³ Scottish Parliament Equal Opportunities Committee, *Official Report*, 29 May 2012, Col 439.

¹²⁴ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 599.

general practitioners and others to use ways of improving patient access and information sharing.”¹²⁵

110. On establishing consistent practice across local authorities on site management, he explained that—

“In the past couple of months, we had a meeting of a group of stakeholders on the issues of sites and illegal encampments. The aim was to consider how to spread more widely the elements of good practice in some local authority areas in addressing those issues. The first meeting of the group took place a couple of weeks ago. From that, there has been a recognition that we need to do more on the guidance that is issued to local authorities and to look at some of the good practice that could be utilised in other council areas. We will work with COSLA and the other stakeholders to consider how the good practice that exists in some local authority areas can be used in other areas.”¹²⁶

Conclusion

111. We are extremely concerned to hear that, where there have been positive outcomes and successful engagement with Gypsy/Travellers during initiatives, there have generally been limited long-term results due to lack of on-going support. Most worrying is the effect this has had on the morale of Gypsy/Travellers, and their trust in both the Scottish Government and public services’ ability to help them. We urge the Scottish Government and NHS Health Scotland, in developing any new engagement initiatives, to ensure that such initiatives are sustainable and plan for both the growth of communities and the transient nature of some Gypsy/Travellers’ lives.

112. We believe that one of the clearest ways to raise awareness of Gypsy/Travellers’ health and social care needs and tackle discrimination is through clear leadership, both at a national strategic level and on a smaller scale within individual departments and practices. Nationally, we recommend that the Scottish Government continue to take into consideration the distinct needs of Gypsy/Travellers in ensuring that policies are open and accessible to all.

113. We have heard of the positive benefits of clearly recognising Gypsy/Travellers as a distinctive group and establishing the term ‘Gypsy/Traveller’ as acceptable terminology, however, more consistency is needed in the use of this terminology. We call on the Scottish Government to review the use of appropriate language within its own documentation to ensure that a strong example is set to other public bodies, and to conduct a review into other terminology related to Gypsy/Travellers to establish similar accepted terms as soon as is practicable. For instance, the term ‘unauthorised camp’ has negative connotations, and we hope that the Scottish Government will work with Gypsy/Travellers to agree on an acceptable term using positive language.

¹²⁵ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Col 594.

¹²⁶ Scottish Parliament Equal Opportunities Committee, *Official Report*, 26 June 2012, Cols 595-596.

114. **Good examples have been given of strong leadership at a management level, and we recommend that those delivering public sector services, including healthcare practices, and guidance issued by professional bodies, must ensure the following:**

a) facilitating a flexible approach to working with individuals, which would benefit Gypsy/Travellers who may need more support in, for instance, understanding medication or form-filling;

b) taking a hard line on any discriminatory behaviour towards Gypsy/Travellers – such behaviour must be dealt with in exactly the same way as racial discrimination towards any other minority ethnic group;

c) ensuring that policies regarding GP registration and treatment take into account cultural sensitivities and do not indirectly discriminate against Gypsy/Travellers, for instance, by requiring a fixed address; and,

d) encouraging cultural awareness through awareness-raising activities such as staff training and informal open days with Gypsy/Travellers where practitioners can get to know their local Gypsy/Traveller communities and establish what approach to care works best for them.

FINAL CONCLUSION

115. **Our report has found that, in spite of the various reports and initiatives of recent decades, little has changed for Gypsy/Travellers. Our finding has been guided by evidence outlining repeated failures: recommendations have not been implemented, initiatives have often been small-scale or short-term and, according to Gypsy/Travellers themselves, they have been fighting the same battles for decades. Access to health and social care alongside other public services must be universal; it is clear that this is not the experience of Gypsy/Travellers living in Scotland today. We look to the Scottish Government to take the strategic lead, with speed and commitment, in making real, significant changes to the lives of Gypsy/Travellers and, by taking positive action to improve their future, to begin to earn Gypsy/Travellers' trust.**

ANNEXE A: EXTRACTS FROM THE MINUTES OF THE EQUAL OPPORTUNITIES COMMITTEE

5th Meeting, 2012 (Session 4) Tuesday 20 March 2012

Inquiries on Gypsy/Traveller issues The Committee will consider its approach to its Gypsy/Travellers and care inquiry [...].

6th Meeting, 2012 (Session 4) Tuesday 27 March 2012

Gypsy/Travellers and care: The Committee took evidence from—

Florence Burke, Director for Scotland, The Princess Royal Trust for Carers;
Alex Cole-Hamilton, Head of Policy, Aberlour Child Care Trust;
Suzanne Munday, Director, MECOPP;
Alex Murphy, Service Manager, Alzheimer Scotland;
Jack Ryan, Chief Executive, Crossroads Caring Scotland.

7th Meeting, 2012 (Session 4) Tuesday 17 April 2012

Inquiry witness expenses: The Committee agreed to delegate to the Convener responsibility for arranging for the SPCB to pay, under Rule 12.4.3, any expenses of witnesses in its inquiries into (a) Gypsy/Travellers and care [...].

9th Meeting, 2012 (Session 4) Tuesday 15 May 2012

Gypsy/Travellers and care: The Committee took evidence from—

Linzi Ferguson, MECOPP;
Lizzie Johnstone;
Michelle Lloyd, MECOPP;
Mary MacDonald;
David McDonald;
Roseanna McPhee;
Shamus McPhee;
Fiona Townsley;
Susan Townsley.

10th Meeting, 2012 (Session 4) Tuesday 29 May 2012

Gypsy/Travellers and care: The Committee took evidence from—

Linda Irvine, Strategic Programme Manager, and James Lambie, Practice Nurse, Edinburgh Access Practice, NHS Lothian;
Dr Iain McNicol MBE;
Joan Watson, Liaison Health Visitor West Lothian Gypsy Travellers, West Lothian CHCP;
Lesley Boyd, Health Inequalities Manager, Chair of NHS Lothian Gypsy and Traveller Health Steering Group, NHS Lothian;

Kenneth Leinster, Head of Community Care & Housing, South Ayrshire Council;
David McPhee, Commissioning & Contracts Officer, Perth & Kinross Council.

13th Meeting, 2012 (Session 4) Tuesday 26 June 2012

Gypsy/Travellers and care: The Committee took evidence from—

Michael Matheson MSP, Minister for Public Health, Jean MacLellan, Division Head, Adult Care and Support Division, and Alastair Pringle, Patient Focus and Equalities, Scottish Government.

ANNEXE B: EVIDENCE – EQUAL OPPORTUNITIES COMMITTEE

WRITTEN EVIDENCE

[Edinburgh Access Practice](#)
[Edinburgh Access Practice supplementary submissions](#)
[MECOPP](#)

ORAL EVIDENCE

[Official Report, Equal Opportunities Committee, 27 March 2012, cols 321 – 345](#)
(ending with the Convener thanking the witnesses for attending)

[Official Report, Equal Opportunities Committee, 15 May 2012, cols 389 – 429](#)
(ending with the Convener thanking the witnesses for attending)

[Official Report, Equal Opportunities Committee, 29 May 2012, cols 439 – 481](#)
(ending with the Committee thanking the witnesses for attending)

[Official Report, Equal Opportunities Committee, 26 June 2012, cols 591 – 611](#)
(ending with the Committee thanking the Minister for attending)

SUPPLEMENTARY EVIDENCE

[Lizzie Johnstone](#)
[MECOPP](#)
[MECOPP supplementary submission](#)
[Michael Matheson MSP, Minister for Public Health](#)
[Perth & Kinross Council \(148KB pdf\)](#)
[Perth & Kinross Council supplementary submissions](#)
[Stoneyburn Health Centre\)](#)
[Susan Townsley](#)

OTHER WRITTEN EVIDENCE

[Jamielee Devers](#)
[Georgia McPhee](#)

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