The Wheels of Change

A report on the barriers faced by disabled Gypsies and Travellers when accessing the Social Care system



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Report prepared in partnership by: Leicestershire Centre for Integrated Living (LCIL)

Derbyshire Gypsy Liaison Group (DGLG) March 2010

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1. Executive Summary

This report examines the barriers that disabled Gypsies and Travellers face when trying to access Social Care. It was conducted using primary and secondary research methods. Primary research involved 63 face-to-face interviews with disabled Gypsies and Travellers. The interviewers, also members of this community, used a semi-structured discussion guide to complete the 20-30 minute interviews. Secondary research involved exploring the services available through the Social Care system to disabled people in Leicester, Leicestershire, Derby and Derbyshire.

There were a number of challenges faced by the Leicestershire Centre for Integrated Living (LCIL) and the Derbyshire Gypsy Liaison Group (DGLG) when conducting this research with Gypsies and Travellers on issues of disability. Firstly, this community has a lack of trust in the settled community, which meant that LCIL would not be able to have direct access to this community. LCIL worked in partnership with DGLG which provided in-depth knowledge of the culture and values of this community and provided the access to this community. LCIL provided DGLG with the in-depth knowledge of disability issues and together it was possible to meet the objectives of the research. However, in order to maintain the trust which has been built up, it is necessary to strictly adhere to the confidentiality promised to respondents.

It is apparent that Gypsies and Travellers experience an extraordinarily high incidence of disability and ill health and, furthermore, have an average life expectancy of ten years less than the settled community population.

"In comparison to other population groups in the UK, the health of Gypsies and Travellers is among the worst in the country."

Gypsies and Travellers: Cultural Influences on Health

Many disabled people within this research study are living lives of discomfort. Among disabled Gypsies and Travellers, 35% indicated that they had to endure pain, tiredness, breathing problems and feelings of weakness. Others felt that they were experiencing emotional distress because of their impairment. Many even found that everyday activities

were difficult, with some needing to move to social housing and having to live outside of their community and cultural ways.

The Gypsy and Traveller community is a close knit one and 70% of respondents indicated that they rely upon their family to help them deal with their impairment. However, some of these have dependents themselves. Once again, many rely upon other family members and people within their community to help them raise their own families. Some find this particularly frustrating and describe instances of raised emotions within the family. Family and friends tend to help with everyday chores such as cooking, washing, cleaning, dressing and providing transportation.

The overall lack of information accessible to the Gypsy and Traveller community adds to the inconsistency of support available. However, living in a close knit community has advantages to disabled Gypsies and Travellers which may not be experienced by some disabled people in sectors of the settled community.

Of concern though, are the 24% of respondents who do not have any help at all from their local community. Some of these and others tend to turn to organisations such as the Gypsy Liaison Groups for support, mainly because they can be assured of dealing with like-minded people who understand their values and culture.

Support from outside of the local community, in the form of the Local Authority's Social Care system, the Voluntary and Community sector, generates mixed feelings amongst respondents. Within this research, 68% of respondents indicated that the main type of support outside of their community is from the medical profession. Other types of support currently being received, if seldomly, take the form of disability equipment, financial assistance (benefits and pension), carers, housing and educational services. 40% have not had any support recently from outside their local community. This implies that, outside of medical services, there is limited support from Social Care providers for Gypsies and Travellers. There is a lack of trust in health professionals to provide appropriate care or doubt in their willingness to engage with community members.

The experience of disabled Gypsies and Travellers differs significantly from disabled people living in the settled community. Fundamentally, Gypsies and Travellers lack awareness and understanding of the support that is available to them. 50% of respondents "do not know of any services that are available" and a further 8% felt that "there would not be any services available at all".

Disabled Gypsies and Travellers were asked to describe the type of services that would benefit them. 27% answered that they did not know, 16% did not consider any services to be useful and a further 30% thought that medical services would be the only ones useful to them. These statistics reflect the low levels of awareness and understanding of the services which should be available to disabled people in this community.

Many Gypsies and Travellers value a way of living which is distinct from those in the settled community. Therefore, disabled people within the Gypsy & Traveller community have limited opportunities to interact with other disabled people. Consequently, this reduces their opportunity to share experience or pass on knowledge about support which might be available to them.

Disabled Gypsies and Travellers tend not to mix with people in the settled community. This is due to a number of factors: lack of trust by both parties; some headline-grabbing discriminatory practices and many unsubstantiated myths about Gypsies and Travellers. It is therefore unlikely that people from this community would welcome the intervention of public bodies. Many may not ask for help for fear that this means that they have to "settle" in order to receive any help with their impairment or that their lives may be forced to change, making it difficult to follow their beliefs and values. Respondents felt that people from outside their community do not understand their culture or appreciate their values.

Some Gypsies and Travellers have poor literacy skills, particularly those whose formal education has been quite short. After primary school-age, Gypsy and Traveller children are encouraged by their parents to pursue the cultural norms of their community and to learn a trade. This impinges upon their level of understanding of information or funding which is available to disabled people. This also affects their confidence

to pursue services to which they might be entitled. Within the older Gypsy and Traveller population there is poor understanding of computers, ruling out the use of online form filling and other uses of Information Communication Technology.

75% of respondents have never considered approaching an organisation outside of their community. The main reasons are summarised below:

- A lack of knowledge about the types of services available to disabled people and where to find any information, compounded by poor literacy skills.
- Gypsies and Travellers are not comfortable dealing with strangers.
- This community values privacy and many do not like discussing private or business affairs with people from organisations or even with the settled community as a whole.
- Gypsies and Travellers do not feel that people from the settled community understand their way of life and culture.
- Some respondents with particular impairments do not consider themselves to be disabled, which is a similar situation within the settled community.
- Travellers moving around the country do not feel it is worth applying for services, particularly when they are likely to move on again.

50% of disabled Gypsies and Travellers felt that external organisations either "could not" or "would not" help them claim Social Care benefits because they were Gypsies and Travellers. Some cited examples such as lack of documented evidence of their existence (e.g. Birth Certificates and National Insurance numbers) as a barrier to obtaining help from government authorities.

The Social Model of Disability¹ describes four main barriers to disabled people:

- 1. Access to information
- 2. Organisational structure
- 3. Environment
- 4. Attitudes

The main barrier to accessing Social Care for 56% of respondents is considered to be poor literacy skills and understanding. Many were also unsure of how to find out information about services and benefits. Almost half the number of respondents felt that perceptions of Gypsies and Travellers by the settled community posed a barrier to obtaining services and dealing with organisations. A lack of understanding of the culture and appreciation of the values of their community has led to many forms of discrimination. For example, taxi drivers tend not to want to deal with Gypsies and Travellers.

Some disabled Gypsies and Travellers find it difficult to deal with organisations and institutions, particularly if they find themselves being passed around or transferred to different departments or people. This is often compounded by the fact that respondents are often unsure about what it is they actually need. Some people, particularly older ones, do not have access to computers in order to search for information online. Another barrier for some disabled people in this community is the difficulty experienced when opening bank accounts or registering with doctors or dentists, especially those who follow a travelling path or those that do not have documents of identification. Finally, a lack of legal sites for Gypsies and Travellers can be problematic when trying to access key services such as health care.

73% of respondents felt that the barriers faced by disabled Gypsies and Travellers are worse than those faced by disabled people in the settled community. Many felt that they have or would be treated as inferior to people outside of their community mainly due to misconceptions, myths and unsubstantiated media coverage.

¹ The Social Model of Disability, Department of Health

87% of respondents are not aware of the services provided by Social Care and had not heard of the Personalisation of Services. Even though interviewers proceeded to give a short summary of Personalisation, 40% of respondents stated that they did not understand what was being described to them. Disabled Gypsies and Travellers thought that there would be a number of barriers to accessing these services:

- Poor literacy skills impeding the understanding of information and being able to fill in forms
- A lack of anyone to help them apply for this benefit
- An aversion to giving strangers information about their personal life or business affairs
- Some disabled Gypsies and Travellers do not have bank accounts
- Lack of experience using computers or communicating online, particularly for older generation Gypsies and Travellers
- · Lack of trust in the settled community
- Lack of trust in new ways of doing things
- Lack of trust in Social Services or other government organisations

The current system is not flexible enough to meet the needs of people who are travelling. Transferring responsibilities for services and benefits to which Gypsies and Travellers are eligible from one local authority area to another continues to be a major barrier. Furthermore, frequent eviction is clearly likely to have an adverse affect on the health of older generation Gypsies and Travellers due to the disruption this causes. There is currently no provision for carrying entitlement to Personalised Services from one authority area to another. Research has found that there is a reluctance of GPs to register members of travelling communities without a fixed address. ²

T TZ

² I Know when it's raining

2. Objectives

This research project has been commissioned by the Equality and Human Rights Commission (EHRC). Leicestershire Centre for Integrated Living (LCIL) worked in partnership with the Derbyshire Gypsy Liaison Group (DGLG) to carry out this research.

Whilst the original objectives were to investigate the Gypsy and Traveller community's perspective on the personalisation of social care, it was apparent from initial discussions that this sector of the community finds it difficult to access the care that they need and consequently tends not to benefit from services to which they might be entitled. Moreover, a large proportion of this community has no knowledge of the social care services available to disabled people and how to get information from service providers. It was decided, therefore, that it was a priority to investigate the fundamental barriers to accessing the social care system.

The objectives of this research were consequently adapted to encompass the following:

- To establish the nature of the barriers and problems experienced by disabled Gypsies and Travellers when trying to access the Social Care/Services system. This includes services offered by other providers including Voluntary and Community sector organisations.
- To determine the effects of an impairment on the everyday lives of disabled Gypsies and Travellers and the subsequent effects on their family.
- To find out how this community currently receives the support they need to deal with their impairment.
- To establish the level of awareness of services available to disabled people in the Gypsy and Traveller community.
- To determine the types of services required by disabled people in this community and to establish their access needs.
- To consider the likelihood of disabled Gypsies and Travellers using external organisations to help them deal with their impairments.

- To look at the potential difficulties that disabled people in this community may encounter when trying to access Social Care. Furthermore, to determine whether they feel that they would experience the same barriers as disabled people in the settled community.
- To determine awareness and perception among disabled people in the Gypsy and Traveller community of the Personalisation of Services.



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3. Methodology

There were a number of challenges faced by LCIL and DGLG when conducting this research with Gypsies and Travellers on issues of disability. At the outset of the project, LCIL and DGLG spent valuable time learning about each other's way of life, issues and difficulties. For example, LCIL provided training on the Social Model of Disability and DGLG provided valuable background on the culture and values of the Gypsy and Traveller community.

There were other challenges encountered within this partnership. Firstly the Gypsy and Traveller community has a lack of trust in the settled community, which meant that LCIL would not be able to have direct access to this community. LCIL worked in partnership with DGLG which provided in-depth knowledge and experience of the culture and values of this community and subsequently, access to this community. LCIL provided DGLG with the in-depth knowledge of disability issues so that together it was possible to successfully meet the objectives of the research.

LCIL and DGLG have built up a strong working relationship during this project, which was based upon mutual trust and respect for issues faced by Gypsies and Travellers and disabled people. Together, the two organisations have been willing to learn and to improve each other's knowledge. Any preconceived ideas have been discussed and either substantiated or corrected so that each party is more informed.

Consequently, the partnership has built up considerable knowledge and experience of the values of each other's respective way of life. However, in order to maintain the trust which has been built up, it is necessary to strictly adhere to the confidentiality promised to respondents.

This research study was conducted using both primary and secondary research methodologies.

Primary research:

Face-to-face interviews were chosen as the main method of conducting this research. It was felt that in order to gain an insight into the perceptions of Gypsies and Travellers it was necessary to obtain first-hand opinions of this community. DGLG's past experience of research within their community provided valuable insight into the success of different methodologies. Historically, focus groups have not proven to be very successful due to the fact that Gypsies and Travellers are very private individuals and do not like discussing personal circumstances even with other members of their community. It was therefore decided that the most appropriate methodology would be face-to-face interviews. The method is outlined below:

- 63 face-to-face interviews were completed with disabled Gypsies and Travellers.
- 23 interviews took place in Leicester City and Leicestershire.
- 35 interviews took place in Derby City and Derbyshire.
- 5 interviews look place on the borders of Lincolnshire.
- Interviews were conducted by five Gypsy community members using a semi-structured discussion guide designed in conjunction with Leicestershire Centre for Integrated Living, Derbyshire Gypsy Liaison Group, Lincolnshire Gypsy Liaison Group and Leicestershire Gypsy Liaison Council Group. This was a unique project in that it aided the capacity building of fledgling groups. It further developed deeper understanding of disability issues for Gypsy and Traveller groups.
- The discussion guide largely comprised open-ended questions with some closed questions.
- Interviews lasted between 20 and 30 minutes
- In order to achieve a representative sample of disabled Gypsies and Travellers to take part in this research, the sample was stratified by location, age, gender and cultural background.
- Information gathered was interpreted and collated by LCIL and DGLG.

 LCIL and & DGLG abide by the Data Protection Act (1985) and the Market Research Society's Code of Conduct (2005) in relation to storing data and protecting the anonymity of respondents. The respondents were assured that their private information would not be passed on to a third party and would be destroyed once the findings of the report had been published.

Secondary research

This involved the collection of information on Social Care services available to disabled people. Details sought included the location of services, the type of organisation (Local Authority, Community or Voluntary Sector or another provider) and finally if the provision of services is dependent on a specific referral or assessment process and details of any costs that may be involved.



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4. Sample

At the outset of the research the following sample criteria were suggested to interviewers. This was used as a guide to ensure that interviewers chose a variety of respondents from different backgrounds.

Table 1

Selection criteria	Target respondents
Total:	A minimum of <u>60</u> face-to-face interviews with disabled Gypsies and Travellers
Age: 15 – 25 26 – 49 50+	20 respondents 20 respondents 20 respondents
Gender: Males Females	20 respondents 40 respondents
Ethnicity: Irish Travellers Romany Gypsy	20 respondents 40 respondents
Area: Derby/Derbyshire Leicester/Leicestershire	30 respondents 30 respondents

5. Profile of respondents

The following table shows the profile of the disabled Gypsy and Traveller respondents.

Table 2

Location	Respondents
Leicester	7
Leicestershire	16
Derby	13
Derbyshire	22
Lincolnshire	5
TOTAL	63

Type of location	Respondents
Local Authority Site	7
Private Site	23
Local Authority Housing	9
Private Housing	3
Unsited/roadside	19
Not specified	2
TOTAL	63

Age range	Respondents
15 - 25	15
26 - 49	28
50 +	20
TOTAL	63

Gender	Respondents
Male	19
Female	44
TOTAL	63

Gypsy/Traveller	Respondents
Irish Traveller	14
Romany Gypsy	47
Showmen	2
TOTAL	63

6. Definitions

Gypsy & Traveller Language

Gypsy language is known as Romanes. It has its roots from Sanskrit, the ancient language of India.

Gorger, Gaje and Gorgia are all variations of the same word. This word is used to describe non-Gypsies.

The Irish Traveller language originates from Ireland and has no connection with Romani.

Romani and Romany are variations of the same word and are interchangeable.



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Disability³

The Disability Discrimination Act 1995 (amended in 2005) says that a disabled person is someone with "a physical or **mental impairment** which has a substantial and **long-term** adverse effect on his ability to carry out normal **day-to-day activities**, or anyone who has had an impairment in the past."

Further definitions within the Disability Discrimination Act:

Mental impairment:

The term "mental impairment" is intended to cover a wide range of impairments relating to mental functioning, including what are often known as learning disabilities.

Long-term: An impairment has a long-term effect if:

- It has lasted at least 12 months;
- The period for which it lasts is likely to be at least 12 months; or
- It is likely to last for the rest of the life of the person affected.

Day-to-day activities: These are defined as:

- Mobility.
- Manual dexterity.
- Physical co-ordination.
- Continence.
- Ability to lift, carry or otherwise move everyday objects.
- Speech, hearing or eyesight.
- Memory or ability to concentrate, learn or understand.
- · Perception of the risk of physical danger.

³ Disability Discrimination Act 1995, section 1

Personalisation⁴

Currently and historically, a person in need of Social Care services would be assessed (by a Social Worker and possibly several other people) and then informed of the type of support they would receive, from whom, where and when.

For some years now the Government has been moving towards changing that system to one where the person in need of Social Care decides what type of support they will receive, from whom, where and when. This is known as the **Personalisation Agenda**.

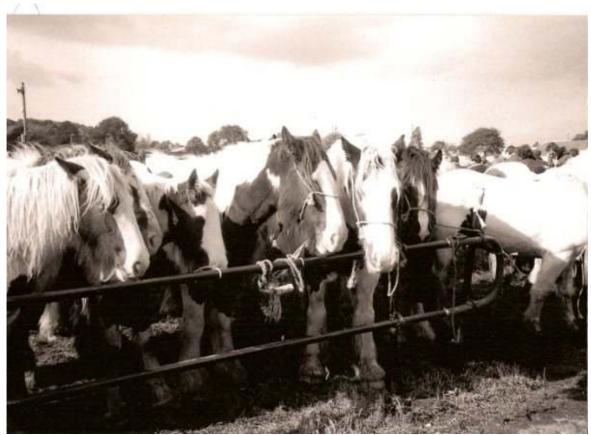
Personalisation means starting with the individual as a person with strengths and preferences. They may have a network of support, have their own funding sources or be eligible for state funding. Personalisation reinforces the idea that the individual is best placed to know what they need and how those needs are best met. It means that people can be responsible for themselves and can make their own decisions about what they require. It also recognises that they should also have information and support to enable them to do so. In this way, services should respond to the individual instead of the person having to fit with the service. This traditional service-led approach has often meant that people have not received the right support for their circumstances or been able to help shape the kind of help they need. Personalisation is about giving people much more choice and control over their lives.

Personalisation itself is not – nor is it just about giving people the option to have personal or individual budgets, although this is an important element. It applies to everyone with a whole range of needs, including those who may not be entitled to publicly funded care. Everyone needs universal access to information and advice to ensure they can choose the best support regardless of how their care is funded. All citizens should be able to access universal services such as transport, leisure and education facilities, housing, health services and opportunities for meaningful occupation.

⁴ LCIL, Eric Day, 8.3.10

To summarise, Personalisation means:

- finding new collaborative ways of working and developing local partnerships, which produce a range of services for people to choose from and opportunities for social inclusion;
- tailoring support to people's individual needs;
- recognising and supporting carers in their role, while enabling them to maintain a life beyond their caring responsibilities;
- a total system response so that universal and community services and resources are accessible to everyone;
- early intervention and prevention so that people are supported early on and in a way that is right for them.



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The Social Model of Disability⁵

Born in the early 1970's, the disabled people's movement has slowly begun to have an impact on today's society and with it has come a new language and an increased understanding of the impacts of disability. For many, the concept of the **Social Model of Disability** has led to a new understanding and has changed their lives.

Whilst many view the model as addressing the need to replace steps with ramps and to increase the width of doorways, the model provides far more. For many people, the model provides a new and empowering way to live their lives, the opportunity to have real choice and control and to be involved in everyday society.

This traditional view of disability is known as the **Medical Model of Disability** or **Individual Model of Disability**, because society views disabled people by their medical problems. It is critical to note this is not just a reflection of the medical world, but of how decisions are made within social care, education, employment and many other areas of our lives. Until recently, the only way to view disabled people was to see their medical condition as their problem, something they will have to make the best of and within which they will have to accept that there are many things they cannot do.

The **Social Model of Disability** starts from a different perspective. It acknowledges that an individual has a medical condition (referred to as an impairment) for which medical intervention may at times be needed. However, the perspective moves on to recognise that every disabled person is a human being and as such is entitled to be treated equally. In doing this, the approach is to identify and challenge those aspects of society that erect barriers preventing disabled people from participating and restricting their opportunities. In order to achieve equality of access and involvement for all, an understanding of specific barriers has emerged. These barriers are broadly defined as **Information**, **Environment**, **Organisational Structures** and **Attitude**.

⁵ Social Model of Disability: Department of Health/National Centre for Integrated Living (NCIL)

Information Barriers – Commonly seen as the need to provide information in a format that meets the needs of the individual e.g. large print, plain English, sign language, pictorial information and other community languages. In reality, this barrier extends to the way that decisions are made and the reliability of the information used should reflect the needs of disabled people.

Environmental Barriers - Not just removing steps and replacing them with ramps, but ensuring that the ramps are built appropriately and meet current and evolving guidelines: that ensure materials that are used in construction take account of sensory needs; with good use of colour contrasts and highlighting; that materials used to provide information in terms of signage allow accessibility to all users; and the need to take advantage of new technology that increases overall access and awareness. Environmental barriers describe the structure in which society operates and that which is created by others, but which takes little or no account of the needs of disabled people.

Organisational Structure Barriers – Refers to the ways in which an organisation operates, how it sets out to meet the needs of disabled people by anticipating demand and training staff to meet the needs of its customer. This is an approach that sees disabled people as customers in their own right and reflects this in the way that services are provided. Positive structures ensure that disabled people have equal access to the process of decision-making and the ability and opportunity to influence decisions.

Attitudinal Barriers – The way that an individual operates and how they allow their own prejudices or the prejudice of their organisations to impact negatively on the rights of disabled people. Changing this barrier can often require a cultural change within an organisation and needs not only to be led from the top, but also must be reinforced throughout the organisation. Such change becomes more effective when the organisation sets out to employ disabled people at all its levels and ensures that the work they undertake is valued and appropriately supported. Attitudinal barriers can be related to institutional discrimination as the impact of attitudes dictates the structure of organisations, the design of environments and the process of creating information.

This approach has now been considered as applicable to all areas of equality.

The social model of disability enables disabled people to look at themselves in a more positive way, which increases their self-esteem and independence. This view runs contrary to the way many disabled people feel, especially if they have recently become disabled or have not had the opportunity to consider alternative views.

Social Model and Independent Living

In developing the Social Model of Disability, consideration was given to the hierarchy of needs that impacted on an individual. Initially these were described as the "Seven Needs" and were first developed by Derbyshire Coalition of Disabled People. More recently, a wider understanding of the impact of different issues has been developed and these are now seen as the need for:

- Appropriate and accessible Information;
- Full Access to our environment;
- A fully accessible Transport system;
- Technical Aids Equipment;
- · Accessible/adapted Housing;
- Personal Assistance;
- Inclusive Education and Training;
- An adequate Income;
- Equal opportunities for Employment;
- Advocacy (towards self-advocacy);
- · Counselling;
- · Appropriate and Accessible Heath Care Provision;

7. Background

7.1 History and Culture of Gypsies and Travellers

Background⁶

The Romani people have lived in England for over 500 years and the Irish community for about 150 years. There is also a Scots Gypsy tradition and this community have at last obtained recognition as an ethnic group. There is intermarriage between the groups. Society finds it difficult to understand and appreciate different cultures so dissemination of correct information on those cultures corrects misunderstandings and helps to eradicate prejudice. Most Gaje⁸ (non-Gypsy) people do not know much about the Romani culture although the Romani have lived in England for centuries.

Amongst Irish Traveller families you may hear words like "Buffer" or "Countryman" rather than Gaje. Gaje (Gorger or Gorgia) means someone who is not of the Romani race and over the years has come to be used to refer to people who do not travel. The aspiration to travel and to continue a nomadic way of life is paramount for Britain's Gypsies and sets them apart from many European Roma, who were forced to settle under communist regimes.

It is often difficult for the majority of society to accept people who behave differently, who do not meet the norms of that majority society. The strange and unfamiliar often confuse. When we speak about equality, this should not mean assimilation into a supposed "mainstream" group without any value being placed on the distinct and varying cultures.

 $^{^{6}}$ An Improved Path to a Better Road (2009) updated the A Better Road Booklet [2002] from DGLG (c)

⁷ The cases that argued ethnic status are in order as follows Romani Gypsies Commission of Racial Equality v Dutton [1989] QB 783 Irish Travellers O'Leary & Others v. Allied Domecq [2000] unreported number CL950275-79 29, 329 August 2000, Scots Gypsy/Travellers K. MacLennan Vs Gypsy Traveller Education and Information Project [2008]S/132721/07

⁸ Gypsy language known as Romanes has its routes from the Sanskrit ancient language of India. Gorger, Gaje and Gorgia are all variations of the same word and is used to describe non-Gypsies

The Irish Traveller language originates in Ireland and has no connection with Romani

There have been attempts in the past at genocide against the Romani. The latest of these periods of persecutions occurred during World War II. At least 600,000 Roma were killed in Hitler's gas chambers. The latest estimate of the number of Roma casualties in that period runs up to two million.

In Britain there has been documented evidence of oppression of the communities and the culture has not been valued. Negative stereotyping has persisted especially in the British media. Recent newspaper stories regarding Gypsies have included "Stamp on the Camps" campaign¹⁰ and "Land Grabbing"¹¹ is reminiscent of the old tales of Gypsies stealing children.

It is difficult to say how many Traditional Travellers there are in Great Britain today; the best estimate is somewhere between 250,000 and 300,000. The first authoritative record of their presence in Britain shows them as being in Scotland as early as 1505, but recent authenticated records and information lead us to believe that the first families were in England sometime between 1437 and 1460.

One of the first authenticated records in England is in 1505. Life was hard for the Gypsy people in Europe before 1500. Laws were passed to expel Gypsies from Spain and Switzerland, and by 1650 most Gypsy people were slaves. In England under the reign of Queen Elizabeth I, Gypsies were expelled along with all freed black slaves. Laws were passed condemning all Gypsies to death. When people were out of work, prices high and peasants were thrown off the land, it was the usual story of looking for someone to blame. Strangers make good scapegoats. In York in 1596 magistrates made children watch while their parents were hanged just because they were Gypsies.

 $^{^{10}}$ 9th of March 2005 the Sun newspaper launched its Stamp on the camps campaign .http://www.thesun.co.uk/sol/homepage/news/article104007.ece

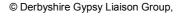
Daily Express article 17th November 2008, headlined Families must sell land for Gypsy Campsites, www.travelerslaw.0rg.uk. January 2009 newsletter No7.

¹² The 1505 date occurs in the *Accounts of the Lord High Treasurer*, 22nd April 1505. The entry reads: "To the Egyptians, by the king is command, vij lib." On 5th July, of the same year, James IV gave to Anthonius Gagino, Count of Little Egypt, a letter of commendation to the King of Denmark, written in Latin. Robert Dawson Historian

After 1780, anti-Gypsy legislation was gradually repealed. Gypsy people became a useful source of cheap labour in the fields, as blacksmiths and as entertainers. Gypsies survived on the margins of society.

After the mechanisation of farming, the lifestyle of Gypsies changed drastically. Not wanted for hop or strawberry picking and other traditional trades, they had to adapt. Again, work was difficult to find for some families and motorisation changed their travel patterns. Mechanisation of the traditional rural work started in the 1950s. The previous sources of livelihood did not provide sufficiently in the rural areas anymore. Industrialisation started the migration from rural areas. The changes in society were also reflected in the Roma population. Many Gypsies moved from the rural areas to the cities and towns.

Over the past few decades the material well-being of some Travellers has improved but there are various issues that have been identified and need addressing, for example the unusually high mortality rate and the fact that life expectancy of Traveller men is ten years less than the national average and twelve years less for Traveller women. ¹³ Legislation in Ireland brought about an influx of Irish Travellers into England in the 1960s and 1970s.





The Wheels of Change, April 2010

¹³ For a good report please see The Heath Status of Gypsies and Travellers in the UK a report to the Department of Health [2004] University of Sheffield www.shef.ac.uk/scharr/research/publications/travellers

7.2 LEGISLATION

Over the years there has been a wide range of legislative measures, designed to stop Romani Gypsy people and Irish Travellers from leading a nomadic way of life, which would have the consequence of eradicating their culture. Such measures date back as far as 1530, with the introduction of the "Egyptians Act" under King Henry VIII. This not only banned the immigration of Gypsies, but also expelled those already in England. Under Queen Elizabeth I, a further Act stated that if "the Egyptians do not give up their ungodly ways they can be imprisoned, transported or executed".

Further Acts which overtly discriminated against Gypsies and Travellers include:

- Highway and Byways Act 1959 which effectively criminalized the Travelling life as families were not allowed to stop on the side of the road.
- The Caravan Sites and Control of Development Act 1960. Many families who had got to know farmers over the years were displaced by this act, since farmers could no longer allow them to stay on their land, as they became eligible for fines if they technically ran a site without a valid site licence.
- The 1968 Caravan Site Act led to the creation of sites by local authorities, but unfortunately many authorities flouted the law and did not build the sites that were needed.
- The Criminal Justice and Public Order Act 1994¹⁴ abolished the 1968 Caravan Sites Act, again criminalising this way of life. This Act also gave the Police increased powers including the right to impound vehicles if there were more than six. Guidelines issued to local authorities emphasised that before an eviction was carried out, health, educational and social needs must be taken into account.

¹⁴ The Gypsy community was caught up in a campaign which they did not want to be part of, but which had consequences for their ability to maintain their traditional way of life. Considerable numbers of young and displaced people took to the road in so-called "Peace Convoys, with an overtly anti-establishment agenda. This had a knock on effect with the Gypsy and traditional Traveller community when the 1968 Caravan Sites Act was abolished. A lot of these itinerant protesters were able to go back to the society that they had come from, but the Gypsy community did not have anywhere else to go

7.3 RECENT LEGISLATION

The Race Relations Act 1976 and Race Relations (Amendment) Act 2000 now also includes Scots Gypsy Travellers. This legislation along with The Human Rights Act 1998 should ensure that Romany Gypsy and Traditional Travellers are recognised as minorities and protected under the law as minorities

It is now a statutory requirement under section 225 of the Housing Act 2004 that there should be an Accommodation Needs Assessment of all Gypsy and Traveller people within each authority. The Needs Assessments in some areas were very poor to start with but have improved over time. A recommendation of this report is that the assessments have to be undertaken in a standardised way across the country in consultation and collaboration with the groups that are in those areas.

In 2006 the new planning guidance circular was issued¹⁶. To a certain degree, there has been an increase in site provision through the planning system, but the majority of these are only temporary permissions whilst the new regional planning system, Regional Spatial Strategies (RSSs) gets underway. In the meantime, some districts and boroughs are objecting to providing pitches even though the identified numbers are very small compared to housing provision.

In 2007 The Showman circular was issued as many local authorities ignored the fact Showmen had been left out of the majority of the early assessments. Showman families have a tradition of travelling and have lived in caravans for centuries. They have their own planning circular, Circular 04/2007Planning For Travelling Show people (some Showmen are Romani also and some have Romani origins).

A Bill was launched by Chris Johnson (Community Law Partnership) to promote security of tenure for local authority Gypsy caravan sites, followed by a petition in 2008. In 2008 during the Housing and

¹⁵ Ibid reference 1

¹⁶ Circular 01/2006 Planning for Gypsy and Traveller Caravan Sites

Renovation Bill, the clause that made local authority sites exempt from the 1983 Mobile Homes Act was removed. At the time of writing this report there is consultation on some aspects of the Mobile Homes Park legislation that many felt were not appropriate for Gypsy sites; (Assignment for example).

Community update

In 2005 The National Federation of Gypsy Liaison Groups was formed specifically to highlight the needs of the elder Gypsy and Traveller people. It offered to host wider network meetings for the former coalition groups. Its aim is also to build capacity within the communities. NFGLG hosts a website for groups to use to put their information on and share best practice.



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7.4 Caravan Counts

The amendment to the Housing Act in 2004 stated that all districts and boroughs should undertake an Accommodation Needs Assessment for Gypsy/Traveller people (including Showmen). Some assessments were not done as well as they should have been. This was partly due to the fact that they had never been done before and partly to a lack of engagement with Gypsy and Traveller people in the early stages However, counties did their best.

It is hoped that in future years these assessments will improve. DGLG recommended that there should be a generic assessment form that can be used throughout the UK. Time and resources were wasted with consultants redesigning questionnaire forms and not enough time was spent with the community. Most areas either took a snapshot of their community or targeted a specified number of Gypsy/Traveller people to interview. There was no county in the East Midlands that attempted to interview all or even the majority of Gypsy and Travellers.

According to the government statistics of the The Bi-annual Count of Gypsy and Traveller Caravans (July 2009), there are 17,437 Gypsy and Traveller caravans in England. Of these, 13,708 are on authorised sites (either private or rented); 2,192 are on land owned by Gypsies and Travellers, but without current planning permission; 1,537 are on land which is not owned by Gypsies.

In the East Midlands there are 1,402 caravans. Of these, 1,007 are on authorised sites (either private or rented); 227 are on land owned by Gypsies and Travellers, but without current planning permission; 168 are on land which is not owned by them. In Leicestershire and Derbyshire (where this survey primarily took place) there are:

359 caravans in Leicester and Leicestershire.

141 caravans in Derby and Derbyshire.

According to many Gypsy and Traveller Groups, these statistics may be underestimated. Therefore they need to be treated with caution. There is evidence that some families were not counted for a variety of reasons including a lack of knowledge as to where a family may be located or families not being there on the day of the count.

7.5 Health of Gypsies and Travellers – an Overview

There is a considerable amount of research into the health of Gypsies and Travellers. The objective here is to summarise just some of the key points. In summary however, it is accurate to say that the health of Gypsies and Travellers is far worse than that of the settled community. Some extracts from research reports are shown below.

- 38% of a sample of 260 Gypsies and Travellers suffer with long-term illness, compared with 26% of a similar sample in the settled community. There is a higher occurrence of arthritis, asthma, chest pain. People within this community are three times more likely to have a chronic cough or bronchitis (even after smoking has been taken into account). 25% indicated mobility problems.¹⁷
- There is a higher incidence of strokes, heart attacks and diabetes amongst the Gypsy community.¹⁸
- There are far higher rates of anxiety and depression and ...
- There are higher risks from cardiac disease especially for Gypsy and Traveller men.¹⁹
- Gypsy and Traveller women, on average, live 12 years less than women in the settled community and men 10 years less.²⁰
- Only 30% of Irish Travellers live beyond their 60th Birthday.²¹ Only 3% of Gypsies and Travellers in Leeds are aged over 60.²²
- Infant mortality is three times higher than that of the settled community. 23 There are higher rates of miscarriage and stillbirths. 24

¹⁷ Parry et al, (2004) The Health Status of Gypsies and Travellers in England, University of Sheffield

¹⁸ MacRedie S and Taylor L (1995) Gypsies and Travellers in North Derbyshire: A report on Travellers' Health, North Derbyshire Health and Derbyshire Gypsy Liaison Group

¹⁹ Roberts et al (2007) Working with Gypsies and Travellers: A Partnership Approach

²⁰ Crawley H (2004) Moving Forward: The Provision of Accommodation for Travellers and Gypsies

²¹ Brack J and Monaghan S (2007) Travellers' Last Rights

²² Baker M (2005) Leeds Baseline Census 2004-2005

²³ Baker M (2005) Leeds Baseline Census 2004-2005

²⁴ Parry et al, (2004) The Health Status of Gypsies and Travellers in England, University of Sheffield

FINDINGS



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8. Gypsies and Travellers: Type of Disability

This survey includes responses from Gypsies and Travellers with the following impairments or conditions. The main type of impairment occurring was that of physical impairment, followed by mental health impairment and then sensory impairment.

Table 3

Type of Impairment	Respondents
Physical impairment	71
Mental health impairment/Learning disability	9
Sensory impairment	6

NB: Respondents may indicate more than one condition or impairment.

9. Current Situation for Disabled Gypsies and Travellers

Disabled Gypsies and Travellers have already made some changes to the way they live, many of which have been self-funded. These are summarised in the table below:

Table: 4

	No. of respondents
Shower/bathing facilities	7
Equipment/modifications	20
Move into social housing	6
Car/mobility scooter	2
Other equipment or facilities	10

NB: Some respondents may have made more than one change to the way they live.

10. Access Needs

Current Access Needs include:

Table: 5

Access Need	No. of respondents
Equipment/adaptations	21
Disabled parking badge/transport	12
Shower/toilet/bathing/cooking/laundry facilities	8
Personal assistant/nursing care	3
Large print	2

NB: Some respondents may indicate more than one access need

11. Disability: Its effects on the everyday lives of Gypsies and Travellers

Respondents were asked "How does your impairment affect your everyday life?" 22 respondents indicated that they are in pain, tired, felt weak or could not breathe. 15 respondents said that they have difficulty in walking, climbing stairs, getting out of bed, bending or lifting. Others experience emotional distress such as depression, anger, worry, upset or feelings of helplessness.

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"I feel helpless and angry."
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Everyday activities such as driving, working, getting washed, dressing and fastening buttons are a struggle for many. Furthermore, some thought it a nuisance to have to take medicine or inject themselves with insulin on a daily basis.

Some Gypsies and Travellers have had to move into social or private housing mainly because the Social Services system finds it hard to meet the needs of this community. Social Services have faced a number of challenges when liaising with the Gypsy and Traveller community. Firstly, there is a fundamental lack of understanding and appreciation of the values and way of life of this community and, very importantly, how these differ from the issues faced by disabled people in the settled community. Secondly, no line of communication has been successfully established other than via the Gypsy Liaison Groups. However, Gypsy Liaison Groups, unless sufficiently resourced, would not be able to provide this valuable service to disabled Gypsies and Travellers. Current forms of communication do not address the issues of poor literacy skills and a lack of knowledge of how to get information and help. Consequently, this has lead to a number of Gypsies and Travellers being moved into social housing, which removes this group from their community and creates an isolated environment for these individuals.

[&]quot;It makes me depressed that I can't do things with my children."

[&]quot;Everyday is awful, I can't do anything anymore."

"We are living in a bungalow with lots of adaptations for disabled people, but I miss my friends, family and the community."

"Looking after a trailer and moving around is hard physically (carrying water, winding jacks). It's difficult these days."

"I don't have the same life as boys my age (no girlfriends)"

"It takes such a long time to get washed and dressed."

"I need to take full syringes everywhere with me."

"I have had to give up my job."

For many though, their impairment is something that they have learned to live with due to lack of support. Others are frustrated in that they have to rely upon carers or their family for help. Some have experienced difficulty with being able to read, fill in forms and read instructions on medicine bottles.

"I just have to cope and get on with things."

"I need someone with me all the time."

"My children have to read things for me."



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12. Disability: Its effects on the families of Gypsies and Travellers

Of the respondents to this survey, 18 stated that they rely upon other members of their family for help with their own children. However, Gypsies and Travellers indicated frustration with the effect that their impairment has upon their family life. Furthermore, some find that their impairment affects the way that they interact with their family and that emotional responses and angry reactions can sometimes prevail.

"I get very tired all the time."

"I struggle to get the children to and from school."

"I can't sit with my family and eat a meal."

"I can't help my children to read."

"I'm often too busy coping with my condition to help them."

"I can't play with my kids."

"I get very upset, especially if they're noisy."

"I'm not always very calm."



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13. Support Network

Some respondents take advantage of the support offered by Social Care services, but many rely upon support from their local Gypsy and Traveller community.

13.1 Support from the local Gypsy & Traveller community

Gypsies and Travellers tend to call upon their local community for help with their impairment. The primary source of care is the family, including husbands, wives, children, brothers, sisters and in-laws.

70% of respondents indicated that family or friends help them deal with their impairment. 6% indicated that they would turn to DGLG or Leicester Gypsy Council Liaison Group (LGCLG) for assistance. However, 24% said that there was no one to help them in their local community. Some of these people are from the older community and they have to manage without any regular assistance from family, friends or outside organisations. They just struggle on with no assistance. Furthermore, this could be one of the main contributors to the shorter life expectancy experienced by this sector of the population.

"We are a very close family and we look after each other."

"I am dependent upon my mum, she is my carer."

"We look after our own."

"My wife looks after me, but she's not well either."

"DGLG help us sort out a lot of things."

"I want to move back to Derbyshire to be with my family, so that they can help me."

13.2 Types of support from the local community

The type of help provided by the local community includes:

- Cooking, washing, cleaning and shopping;
- Transportation;
- Reading, writing and filling in forms;
- Taking children to school;
- Dressing;
- Physical support (e.g. lifting);
- Emotional support.

"My sister takes the children to school for me."

"My children help me to read letters and forms – a lot of us can't read."

"My mum and sister help me clean the trailer."

"Other men help me deal with toileting if I can't manage."

"I can't fasten buttons, others have to do that for me."

"I have to rely on others for lifts and transport – there's no public transport here and taxis won't come."

"I am disabled and also care for my wife."

Some Gypsies and Travellers indicated that they would turn to DGLG or LGCLG for help with appointments, benefits, health services, form filling, transport, driving licences, housing, planning permission etc.

"DGLG helped me to get a bungalow, sort out my benefits and get me a driving licence."

During this research, the Gypsy Liaison Groups picked up eight one-toone support cases from this survey. In particular, one urgent case meant that the interviewer had to take immediate action and took the respondent to see a Doctor during interview (please see Section 20 for case studies).

This highlights a significant need for appropriately resourced frontline support. Gypsies and Travellers are, by definition, a travelling community which means that effective support has to be designed in such a way as to respect the culture and needs.

13.3 Support from outside the Local Community

This could include Social Care services provided by the Local Authority, NHS, Community Sector or Voluntary Sector.

68% of Gypsies and Travellers (43 respondents) indicated that the main type of support from outside of their local community is from the medical profession, including doctors, specialist doctors, hospitals, clinics, physiotherapists, chemotherapy/radiotherapy, health visitors, psychologists, nurses and specialist nurses. However, there is a lack of trust in health professionals to provide appropriate care or doubt in their willingness to engage with community members.

A further four respondents indicated support from certain organisations e.g. MacMillan Cancer Support, The Red Cross, MS Association and the Samaritans. Six respondents stated that they received some form of financial help in terms of a pension or disability allowance.

A few individual cases specified that they had received help with particular types of equipment, (e.g. hearing aids, wheelchairs, adaptations to a car, mobility scooter and a walk-in shower). A few respondents mentioned a carer, private carer, laundry service, Sure Start, Social Services, housing and the Traveller Education Service (TES). For those who have received support, it is often following contact with DGLG, word of mouth or via the Traveller Education Services. TES is a good source of information for individuals especially if there is a child with disability or young adult etc. It would seem, therefore, that where there are children or young people in a family, the level of support is greater than for the older Gypsy and Traveller population.

40% (25) of respondents have not had any support outside their own community. The main reasons, which are explored later in the report, are:

- Discrimination and poor treatment from people in the settled community
- Lack of trust in the settled community and public sector organisations
- The Gypsy and Traveller community is one which values its privacy
- This is a community which has a strong ethos of looking after its own.



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14. Awareness of services available to disabled Gypsies & Travellers

Respondents were asked "What sort of services are you aware of that Social Services or the Voluntary or Community Sector provides for disabled Gypsies and Travellers?"

Responses to this question highlight a considerable lack of knowledge of the types of services available.

Almost 50% of respondents did not know of any services that were available to disabled people in this community. 8% did not feel that any services would be available to them at all. A further 14% thought that the main type of support was from the medical profession.

Some comments are noted below:

"We don't get told what is available."

"There may be help available, but then we could move to a different place where there is no help."

"They provide Home Help, but I wouldn't have a stranger in."

"Are Social Services them that takes children in to care?"

"I don't know – but I know there's so much more out there."



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The following table notes respondents' answers.

'What sort of services are you aware of that Social Services or the Voluntary or Community sector provides for disabled Gypsies and Travellers?'

Table 6

Type of Service	No. of respondents
Don't know	31
None	5
Medical services (doctors, nurses, hospitals, clinics)	9
Carers/home help/meals-on-wheels	8
Special centres/community places/respite care	5
Wheelchairs/mobility scooter/adaptations	5
Disabled parking badges/transport	3
Other services	6

15. Services required by Gypsies and Travellers

Respondents were asked "What sort of services or facilities provided by an outside organisation (e.g. Social Services, Voluntary & Community Sector) do you think would help you deal with your condition?"

27% of Gypsies and Travellers did not know what sort of services would help them deal with their condition. A further 16% thought that there would not be any services that would be useful to them. This reflects the findings from the previous question, where 50% of respondents did not know what was available to them and a further 8% did not think that anything was available to them.

A number of Gypsies and Travellers highlighted that a high degree of privacy is important in their culture and that they do not like "outsiders" knowing their business. Others stated that people from outside their local community did not understand or appreciate their ways and culture. Some indicated that the forms took too long to complete, were too complex and time consuming. Furthermore, some older generation Gypsies and Travellers cannot read or cannot use computers.

The comments noted below reflect these statistics.

"I just have to get on with it."

"We wouldn't do anything with Social Services – they don't understand our ways and they take our children."

"We would only deal with DGLG."

"There are probably things that they can do, but it takes up too much time."

"They only sort out children."

"I had a bath nurse, but she couldn't be relied upon."

"I don't need anything, its private – I don't want the world knowing my business."

"None, Social Services are no good."

30% of Gypsies and Travellers thought that the only services useful to them were from the medical profession.

The following table notes respondents' answers.

'What sort of services or facilities provided by an outside organisation (e.g. Social Services, Voluntary & Community Sector) do you think would help you deal with your condition?'

Table 7

Type of Service	No of respondents
Don't know	17
Doctors/medical/hospitals	19
None	10
Carer/help	4
Therapy and exercise	4
Support groups	3
Planning permission/relocation	2
Other services, e.g. transport, adaptations	4

16. Likelihood of using external organisations

Those respondents who have never had any help from outside their own Gypsy and Traveller community were asked if they had ever considered approaching external organisations for support or help with their condition. 38 respondents (or 75% of those that have never had any contact) have not considered approaching an organisation outside their community.

NB: These organisations could include the Local Authority's Social Services, voluntary sector organisations and community organisations.

Have you ever considered approaching external organisations for support to help you with your condition?

Ta	h	le:	8
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Yes	13	25%
No	38	75%
TOTAL	51	100%

75% of respondents have not considered contacting an organisation outside their community. The main reasons for this are:

- A lack of knowledge about the types of services available to disabled people and where to find any information.
- This community is not comfortable dealing with strangers. Many are particularly private people and do not like discussing personal business with people from organisations.
- Gypsies and Travellers do not feel that people from the settled community understand their way of life, culture and values.
- Some people with particular impairments did not consider themselves as disabled people.
- Literacy skills can be poor within this community.
- Travellers moving around the country do not feel that applying for benefits would be of any use to them, particularly as they may have moved away from the county before a benefit is granted.

Some comments from Gypsies and Travellers are noted below:

"I don't know anything about what they do."

"I'm not happy dealing with strangers."

"I would not talk to anyone from the settled community."

"We wouldn't feel comfortable with Gorgias helping us with some stuff."

"I don't want any help from them, we manage alright."

"I don't really want to get involved with them."

"We need particular help and Gorgias wouldn't know how to help us with things."

"I would go through DGLG."

"I'm too old to learn all that stuff now."

"I am not disabled."

"Don't know because I can't read or write."

"Don't know – we move about too much to even bother."

"I wouldn't bother with clubs and groups."

"I've never had a penny off anyone."

"I don't need anything, its private – I don't want the world knowing my business."



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17. Perceptions of service provision

Respondents were then asked "If you contacted the Local Authority or other organisations, do you think that they would help/support you with your condition?"

Table: 9		
YES	15	24%
NO	24	38%
Don't know	8	13%
No reply	16	25%
TOTAL	63	100%

Only a quarter of respondents thought that external organisations would help them with their condition or impairment.

- Some felt that external organisations "could not" help
- Some felt that external organisations "would not" help because they were dealing with Gypsies and Travellers.
- A further quarter of respondents did not reply. The reason for this 'no reply' is either because respondents were already in contact with Social Care services or because some were not sure about the question they were being asked.

Some of these respondents felt that no help was available at all for their condition:

[&]quot;There's not much they can do."

[&]quot;I don't think there's anything they can do for me."

[&]quot;No one knows about this illness. So I'm not sure help is out there for me."

Others felt that help would not be available *because* they were Gypsies and Travellers.

"They are not interested in Travellers who have not got a fixed address."

"I don't stay in one place long enough to get any help."

"They do not want to help us."

"I don't know if they would help me because I'm a Gypsy."

"I don't think I'll be able to get anything as I can't get a National Insurance number – I'm worried I won't get a pension."

"They probably would try, but it's a waste of time — close family are better. Gypsies don't like Social Services — we're frightened of asking for support — they have a reputation of taking our children into care."

"I was given leaflets to read, but I can't read."

"You can't trust the people at day centres. It's also hard to get to these places – taxi drivers can be abusive."

"I know about Social Services, but would not want to use them." "Gypsies and Social Services just don't mix."

"I have Dyslexia, but the teachers just said I was too lazy to learn."



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18. Barriers to Accessing Social Care

This section discusses the potential difficulties that could be experienced by disabled Gypsies and Travellers when trying to access Social Care services (or services from other providers).

The main difficulties experienced by disabled Gypsies and Travellers when trying to access Social Care services centre around problems with being able to find out information, read and understand documents and subsequently fill in any forms (83% of respondents). This is underpinned by a difficulty understanding some of the words or phrases that appear in the forms and literature (41% of respondents). Few documents are available in Easy Read format, despite this being a reasonable adjustment expected of public sector bodies and a requirement of the Disability Discrimination Act.

Twelve respondents indicated that they cannot read or write. Some others have very low levels of literacy. In these instances, providing Easy Read documents would not be sufficient and further measures would need to be undertaken, for example one-to-one assistance, use of visual images and pictures as a means to making information easier to understand.

The perception of Gypsies and Travellers by the settled community is cited by 57% respondents as causing difficulty when dealing with Social Care organisations. This perception stems from a lack of understanding and appreciation of the culture of this community and displays itself in many forms ranging from pretending that they don't exist to ignorance and in more severe cases violence, abuse or damage to property. An example of this is where 20 respondents said that they find it difficult to get taxi companies to offer their services.

Some find it difficult talking to people within large organisations, particularly if they are being transferred to different departments. This is compounded by the fact that disabled Gypsies and Travellers are quite often unsure about what they need, what is available and how they go about getting it. Many people, particularly the older generation, do not have access to computers in order to search for information available online.

Another problem for Gypsies and Travellers is the difficulty they find opening bank accounts or registering with doctors and dentists. The three main reasons for this are:

- Those that are moving around the country and do not have a fixed address find it difficult to obtain the most basic of services
- Some do not have identification documents
- And, once again the propensity for the settled community not to want to deal with Gypsies and Travellers.

Finally, those Travellers who are moving around find it difficult to transfer their entitlements from one Local Authority to another.

The following comments describe some of the problems the accessing Social Care:

"They think we are scum."

"They don't like us and don't understand our culture and ways."

"I can read a bit, but don't understand what I'm reading."

"I never went to school to learn to read or write."

"Everything is a problem when you can't read or write."

"We don't stay on the same site, we move around all the time. So doctors, hospitals and other things can be difficult to find out about."

"Transport can be a real problem. We are not on a bus route and taxis won't pick up from this place as they know we are Gypsies."

"I don't know where to go to get help."

"I deal with DGLG. I can't read or write or remember names. I don't have a bank account and can't open one because I haven't got a Birth Certificate. I don't know anything about computers."

"The older generation people can't use computers."

The following table highlights the potential problems which may be experienced by Gypsies and Travellers when trying to access the Social Care system.

'Please describe what difficulties you have come across or might come across when trying to access Social Care services'

Table 10

POTENTIAL PROBLEM	NO. OF RESPONDENTS	% OF TOTAL
Being able to access/read/understand/fill in info/forms/questionnaires or don't know where to go for help	52	83%
People's perception of Gypsies and Travellers/not wanting to deal with Social Services	36	57%
The terminology/words that are used	26	41%
Access to taxis (taxi drivers refusing to offer services)	20	32%
Problems opening bank accounts/registering with Doctors/Dentists & transfer of records/no mailing address	19	30%
Not being able to talk to the same person/transferred to different depts.	18	29%
Getting answers or responses to questions	16	25%
Transferring any services/benefits between Local Authorities	14	22%
Cannot read or write	12	19%
Accessing information on-line (access to computer/broadband)	12	19%

18.1 Barriers to Accessing Social Care:

Disabled Gypsies & Travellers vs. Disabled people from the Settled Community?

Disabled Gypsies and Travellers were asked whether they felt that the barriers they face in accessing Social Care were similar to the experiences of disabled people in the settled community.

Table 11

	NO. OF RESPONDENTS	% OF TOTAL
Yes	11	17%
No, it's worse	46	73%
Not answered/don't know	6	10%
TOTAL	63	100%

73% of disabled Gypsies and Travellers felt that the barriers that they face when trying to access Social Care are far worse than the experiences of disabled people in the settled community.

Many disabled Gypsies and Travellers felt that they were treated as inferior to disabled people in the settled community.

"Its three times as hard for Travellers, we're treated like third class citizens who have chosen to live like this and therefore we shouldn't be entitled to anything."

[&]quot;We are thought of as inferior and shoved to one side."

[&]quot;They don't like Travellers – they treat us like dogs."

[&]quot;We're treated like second class citizens."

[&]quot;People hate us and don't tell us about any help out there."

[&]quot;Nobody takes the time to listen or do anything to help us."

[&]quot;Nobody cares or wants to know about our ways."

[&]quot;Everyone looks down on us, never trusts us and never listen."

[&]quot;We're just dirt as far as the settled community are concerned."

[&]quot;People don't take time with us they think we're idiots."

Many other respondents felt that another disadvantage is low levels of literacy skills and poor understanding of information.

"If you have to speak to someone you don't know, they don't realise that you cannot read and find it difficult to understand things."

"We don't understand what is out there for us."

"We don't understand our rights."

"We have trouble understanding."

Some Gypsies and Travellers do not like being recognised as being disabled.

"Disabled – we don't like that word – we are what we are."

"We shouldn't label someone this or that. You should look after your own. They are how God made them and we should do the best we can for them."

"I don't like being called disabled. I just got this thing – it makes it sound worse if you say disabled."

Part of the Gypsy and Traveller culture is the value that it places upon privacy.

"We are shy about strangers and personal care."

Many feel that disabled roadside Travellers fair worst of all.

"The barriers for Travellers are worse, especially for those at the roadside."

"If you haven't got a fixed address, it's hard to get anything that you need."

"Those on the side of the road suffer the most."

"Because we move around so much, we are treated differently in different places and Doctors don't understand us."

"It's hard without a postcode."

Some older respondents do not have the proper identification details

"Some of the older people do not have NHS numbers – so they don't exist."

19. Personalisation

19.1 Awareness of Personalisation of services

87% of respondents are not aware of the Personalisation of Services. Out of those eight respondents who have heard of Personalisation, three of them now live in Local Authority housing. Please refer to a definition of Personalisation in section 6.

Table 12

	NO. OF RESPONDENTS	% OF TOTAL
Yes	8	13%
No	55	87%
TOTAL	63	100%

19.2 Perception of the Personalisation of Services

Interviewers described a brief outline of Personalisation and then asked disabled Gypsies and Travellers what they thought the problems might be for their community.

40% of respondents indicated that they were not sure what the problems might be mainly because they did not understand what was being described to them.

Other respondents described a range of foreseeable problems. Disabled Gypsies and Travellers would find it hard to read and understand information was cited as the primary problem (25% of respondents). Consequently, they would find it difficult to complete any necessary forms. Others said that where there was poor understanding of information there was a lack of any help from any person or organisation to improve that understanding.

Other problems highlighted include:

- Many Gypsies and Travellers do not have a bank account;
- Aversion to giving strangers information about personal lives or business affairs;
- Lack of experience of using computers or communicating online;
- Lack of trust in the settled community;
- Lack of trust in new ways of doing things;
- Lack of trust in Social Services or other government organisations.

Some comments include:

"We find it hard to read, understand what things mean and fill out forms."

"When we don't understand, there's no one to explain it, help us or tell us where to go."

"We don't like strangers knowing our business."

"Don't expect us to use computers."

"I don't think Gypsies and Travellers will like it, when they hear Social Services they think that their kids will get taken off them."

"If they don't have a bank account, they're finished before they're started."

Respondents were asked "Would Gypsies and Travellers welcome this new method?"

Table 13

	No. of respondents
Yes	20
No	8
Don't know	23
Maybe	12

[&]quot;They don't trust people and new things."

The views on the likelihood of accepting Personalisation are very wide ranging and most comments were not purely "yes" or "no" answers. Disabled Gypsies and Travellers felt that Personalisation would only work for their community under certain conditions. These conditions include:

- Information needs to be in plain English, including "Easy Read". It may be necessary to present information in an even simpler format;
- Gypsies and Travellers need help to understand Personalisation;
- Help and assistance would need to come from people who understand the culture and issues of disabled people in this community, for example help from Gypsy Liaison Groups;
- Help to find out where to apply;
- Help to find out how to get it;
- It needs to be quick and easy to complete;
- It needs to respect a culture that values privacy;
- There should not be reliance upon the use of computers to find information or on-line completion of forms.

Comments include:

"They will only use it if someone helps them to understand it."

"We need DGLG to help us with things like this."

"It depends, if they understand it and know how to get it."

"They won't bother with the hassle."

"They might not like the intrusion."

"It'll be okay if we know where to go and it's in words we can understand."

"I would welcome this, but we need to have people to go to who we know and understand us (we don't like strangers)."

"They will like it if it means less hassle to get the things we need, if it is more hassle then it won't work."

"Yes, but we need help to understand how to get it. We don't understand current things we could get, let alone any changes to anything."

"Some will be too proud to let strangers have access to their affairs."

20. Case Studies

A selection of Gypsies and Travellers were asked to describe their experiences of dealing with external organisations in more detail.

These experiences are described in the following case studies:

Case one

A telephone call was made by a Gypsy to Derbyshire County Council for information regarding support aids. This experience involved a very long wait on the phone and transfers to different departments using a 'press number' system of options. However, when the respondent was finally able to speak to the appropriate person the response was very good. The response involved promising a visit to see what the respondent was able and not able to do. The respondent would have preferred to talk to someone at the start of the call rather than having to follow a 'press number' system which they found rather confusing.

Case two

In this second case study, the Gypsy and Traveller found particular difficulties with having no NHS number. This was compounded by the fact that the respondent had had to move to a new local authority area and all of the correspondence had been with another area.

"Having No NHS number was a nightmare at first. If it wasn't for a very nice Doctor we would have been lost. I rang the hospital that she was sent to and they had no record, even though we had an appointment. We had to go back to the Doctor and he helped along with DGLG to follow her through the system. Because we had to move, things had to be transferred again. The second hospital was horrible with my so we went back to the first hospital. I couldn't remember any of the names of the Doctors and there were that many different people that we spoke to. It was really hard trying to get the help we needed and we drove hundreds of miles to get to the hospital that was good with us."

Case Three

This Gypsy lady had applied to Adult Care to have a disabled shower unit fitted in her utility shed along with specially adapted steps and rails to help her get in and out of her caravan safely. This request was made over two years ago and has not been carried out. The Gypsy Liaison Group contacted Adult Social Care on behalf of this elderly lady in the autumn of last year. Adult Social Care's response was to confirm by email that this would be a fast track job and be completed within 2 weeks. The officer was expected to contact this lady that same day to confirm progress of the work. This was five months ago and the work has, as yet, never been completed. This lady had been sent a letter which she was meant to sign, however she did not understand what she was required to do and subsequently did not sign the required paperwork. This highlights that poor levels of literacy is a significant barrier to communication between Social Care Services and Gypsies and Travellers. This lady had problems with walking and her balance is not very good. She has already taken a tumble down the steps, which are only made of wooden pallets. A Social Worker paid a visit to this lady in December and she also fell down the slippery outside steps.

Case Four

During an interview for this research project, the interviewer quickly realised that the respondent was seriously ill and needed urgent medical attention. The respondent had not sought medical attention previously as they were too scared to deal with anyone from the settled community and fear about what family and friends may think. Had the interviewer not provided immediate help and assistance by taking this person to the doctors, the respondent's life would have been at risk. The respondent continues to receive medical and psychological assistance and is receiving support from the Gypsy Liaison Group. Although, many Gypsies and Travellers receive support from within their own community, some will hide their condition for fear of the response from their own family and friends. This is particularly so with mental health impairments.



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21. Conclusions and Recommendations

This research was conducted with Gypsies and Travellers who are disabled or have a long-term life limiting illness. Gypsies and Travellers experience an extraordinarily high incidence of disability and ill health and, in turn have an average life expectancy of ten (for men) to twelve (for women) years less than the settled community population.

Within the interview group, many disabled Gypsies and Travellers are living lives of discomfort, enduring emotional distress and struggling with everyday activities. There is a high reliance upon family and the community for support. This could subsequently lead to an inconsistency of support, with the danger that support is given by someone with insufficient experience and knowledge of that precise condition. 40% of respondents had not received any support outside of their own community.

Outside their community the main type of support is from the medical profession. Other types of Social Care services are being accessed, but only by a few disabled Gypsies and Travellers.

The main challenges that a provider of Social Care will face are:

- Lack of awareness and understanding within the Gypsy and Traveller community of the support which is available;
- Limited interaction with disabled people from the settled community reducing the opportunity to share experiences or pass on knowledge;
- Lack of trust in the settled community and particularly in public sector organisations;
- Feelings that people from the settled community do not understand their culture or appreciate their values;
- Poor literacy skills for some Gypsies and Travellers affecting the level of confidence to pursue services to which they might be entitled:
- Poor understanding of the use of computers and communicating via the Internet for older generation Gypsies and Travellers. There is an increasing reliance by public sector organisations to provide information via a computer and online;

- Gypsies and Travellers are particularly private people and many do not like discussing private business with strangers, particularly people from government organisations;
- Travellers moving around the country do not feel it is worth applying for services when they are likely to move on again. There is not current provision for transferring entitlements between Local Authorities:
- Some older people in this community do not have the necessary documents to apply for benefits or support;
- People in this community feel that the settled community have some unwarranted perceptions of Gypsies and Travellers and many feel that they are not treated as well as people from the settled community;
- Some do not have bank accounts or have not managed to register with doctors or dentists, particularly those leading a more nomadic way of life and those without formal personal identification;
- A lack of legal sites can be problematic when trying to access key services such as health care. Furthermore, a lack of action by Public Sector bodies to approve sites does not help this;
- Inflexibility of the Social Care system to meet the needs of Gypsies and Travellers.

Unless these barriers are addressed, they will hamper the success of Personalisation. There is a further set of specific issues which have been highlighted during this research. The current methodology used by Social Services is not conducive to people leading a nomadic way of life. There is currently no provision for carrying an entitlement to Personalised Services from one authority area to another.

Recommendations

The Gypsy and Traveller community can be quite hard to reach and pose particular challenges to deliverers of Social Care.

It is recommended that any changes to service provision, including the introduction of Personalisation, encompass:

- The use of simple plain English on forms and literature
- Forms need to be quick and easy to complete and there should not be reliance upon computerisation of information or on-line form filling.
- Documents produced in 'Easy Read' format
- Information produced as an audio cassette or CD Rom
- Capacity building of groups to provide practical support and assistance to this community. Without this support, Gypsies and Travellers will continue to come across barriers and not take advantage of the services and benefits to which they might be entitled. These groups need to be able to understand and appreciate the values and culture of the community. Gypsy Liaison Groups would be ideally placed to undertake this role, should capacity building allow for an increase in resources. These groups could provide advice, one-to-one assistance, but from a perspective of being integrated and accepted by this community. It is unlikely that Gypsies and Travellers would accept help from anyone outside of their community. This is compounded by the fact that for Gypsies and Travellers to make more use of Social Services they would need a great deal of help in order to apply for service.
- In order for Gypsy Liaison Groups to provide this support to disabled Gypsies and Travellers effectively; they would need the support of an organisation with considerable experience of the issues of disabled people, such as LCIL. LCIL would provide the link between the Gypsy Liaison Groups and the providers of Social Care. LCIL could ensure that the Gypsy Liaison groups are kept up-to-date with current legislation and services available to disabled people. LCIL could also work with the providers to

- ensure that their services are accessible to Gypsies and Travellers.
- The understanding and trust which has been established between LCIL, DGLG and LGCLG throughout this project has created an effective partnership which, in the future, could help improve the lives disabled Gypsies and Travellers.
- In order to address some of the challenges faced by Social Services, individual community members could be trained to promote care/support services and personalisation to the Gypsy and Traveller community.
- The success of Personalisation in this community would rely heavily upon the involvement of Gypsy Liaison Groups providing practical one-to-one support for disabled Gypsies and Travellers.
- Certain elements of Personalisation would need to change considerably in order to be adopted by Gypsies and Travellers. An example of the inadequacy of Personalisation is when the needs of Travellers are examined. In order for Personalisation to work the direct payments need to be transferable from one Local Authority to another.



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Appendix 1: Discussion guide

GYPSY & TRAVELLER RESEARCH PROJECT

Discussion Guide

interview Details:				
Name of inter	Name of interviewer: Interview Date:			
Respondent	Profile:			
Name:	Tel. No	o.:		
Location:				
Type of location: Local Authority site Private site Local Authority Housing Private Housing Unsited/Roadside				
Age band	15 – 25 26 – 49 50 +	Gender:	Male Female	
Туре:	Irish Traveller Romany Gypsy Showmen Roma	Area:	Derby City Derbyshire Leicester City Leicestershire	

INTRODUCTION

We've been asked to look into the barriers and problems experienced by disabled Gypsies and Travellers when trying to access the Local Authority's social care/services system. The interview will take about 15-20 minutes. All responses will be treated in confidence. Individual names will not appear in the report and you can even remain anonymous if you wish. The information that you give me will be held securely by LCIL and will not be passed onto any other organisation or person (Show laminated letter). Once we have finished the interview, would you mind if I followed this up with a short 5 minute telephone interview in about 3 weeks time.

YES (Tel No.?) NO

QUALIFYING QUESTION

Do you experience any of the following disabilities/ impairments or conditions?

Show laminated sheet

If no, end interview.	
Which conditions has respondent highlighted?	_
If yes, continue with interview	

Questions

We'd firstly like to ask you about the type of support you get to help you with your disability, impairment or condition.

Q1. Do you have anyone who helps you from your community?

YES NO

What sort of things do they help you with?

Q2. Do you <u>receive</u> or have you ever received any help from anyone outside of your immediate community? E.g. Social Services, Local Authority YES NO

IF YES, What sort of help do you get?

IF NO, Have you ever <u>considered approaching</u> external organisations for support to help you with your condition? E.g. From Social Services or the Local Authority?

YES NO

IF NO, Do you think that if you contacted the Local Authority they would help/support you with your condition?

YES NO

	sort of services are y ary and Community s		
organisatio	sort of services or fa on (e.g. Social Servic ok would help you de	es, Voluntary &	Community Sector)
Q5. Do you outside the	/ER: ANY IMMEDIAT I require any help in community? sort of support would beive this support from	terms of your c YES you find useful?	ondition from NO

KEY QUESTION

Q6. Please describe what difficulties you have come across or might come across when trying to access social care services?

Interviewer: Below are some of the issues that respondents might bring up. However, only prompt respondent with broad issues like getting information, filling out forms, talking to people, etc. (Prompting directly from the list below would bias the results)

- Not able to talk to the same person/transferred to different departments
- Getting answers or response to queries
- Accessing information
- Being able to read/understand/fill in information/forms/questionnaires
- Transferring any services/benefits between Local Authorities, eg moving between Leicester and Leicestershire or elsewhere
- The terminology that they use
- Problems with opening bank accounts/registering with Doctors and Dentists
- Accessing information on-line (access to a computer/broadband etc)
- Location of services transport issues / Parking disabled parking spaces
- Personal assistants
- People's perception of Gypsies and Travellers.
- Access to taxis

Q7. Do you think that disabled Gypsies and Travellers face the same barriers as disabled people in the settled community?

YES NO

IF NO, what additional barriers do you think disabled Gypsies and Travellers face?

Q8. Have you heard of the new 'Personalisation' of the Local Authorities services?

YES NO

READ OUT

The **Personalisation** of services means that any person who is entitled to support will be able to decide upon and have control over the type of services they receive in terms of social care, housing, benefits, leisure, transport and health needs. People will be able to access the services they need in order to give them independence, dignity and to encourage well-being. It also aims to provide early intervention to prevent problems arising and to give people individual budgets to spend on the type of care that they believe will benefit them the most.

Q9. How do you think that this will affect the Gypsy and Traveller Community?

What problems do you think Gypsies and Travellers will have with this?

Do you think that Gypsies and Travellers will welcome this new service and want to use it?

I would like to ask you how your disability/impairment affects your everyday life

Q10. What sort of access needs do you have? SHOW LAMINATED SHEET FOR EXAMPLES

Q11. How does this <i>impairment</i> affect your everyday I	<i>t</i> affect your everyday life?
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Q12. Do you have any children or other dependents?

YES NO

Has your impairment affected how you manage with looking after your dependents? Please describe.

Do you need to make any adjustments to enable you to look after your children?

Do other members of the family or community help you with such tasks?

Are there any parenting roles that you feel you struggle with or cannot do because of you health/impairment/disability and would you benefit from external support if this was available.

Q13. What sort of special facilities or adaptations have you made to help you with your disability/impairment?

Concluding

Q14. Is there anything else that you wish to add that would help us with this research?

Thank you for your time.

I would just like to reassure you that I will treat all the comments that you have made in the strictest of confidence. I will be ringing you in 2-3 weeks with just a few more short questions (provided respondent has agreed to this).

Once again many thanks and I will speak to you soon.



Leicestershire Centre for Integrated Living



Derbyshire Gypsy Liaison Group Moving Forward

Leicestershire Gypsy Council Liaison Group



Lincolnshire Gypsy Liaison Group



All Group Members of the National Federation of Gypsy Liaison Groups sharing good practice and networking in the regions



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