



“I know when it’s raining”



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Report of the Community - Led Research Project Focussing on the Emotional Health and Well-being
Needs of Romany Gypsies and Irish Travellers

Derbyshire Gypsy Liaison Group

East Midlands Region

COMMUNITY ENGAGEMENT PROJECT: the NIMHE Mental Health Programme.

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Bridie Page, Siobhan Spencer.**

May 2008

Contents

Foreword	2
Focus of Report	3
Project Team	4
Acknowledgements	5
Introduction	6
Executive Summary	11
National Recommendations	14
Background Information	15
What, where and how	18
List of Graphs	19
Case studies	30
In our own Words	37
References	43

Foreword

Delivering Race Equality: An Action Plan for Mental Health Services was launched in January 2005. It is a 5 year action plan to promote equality of access, experience and outcome for Black and minority ethnic communities from mental health services. Gypsy and Traveller communities are included within the definition of Black and minority ethnic and I was delighted that the Derby Gypsy Liaison Group applied to become a part of the Community Engagement Programme. I was both surprised and saddened that there has been very little research undertaken into the mental health of this community.

I am both delighted and honoured to have been asked to write the forward for the report.

Having been involved with DGLG from the start of the project I have seen ideas and individuals grow and develop. Supporting the project team has given me a personal 'glimpse' into the work and life of Gypsies and Traveller communities.

Staff and volunteers at DGLG are to be congratulated on completing the project. The recommendations do not only have implications for commissioning and service delivery locally, but also nationally. I am pleased to announce that this project, design and outcomes have attracted interest internationally.

Well done and many congratulations

Asha Day
Regional Race Equality Lead
Care Services Improvement Partnership East Midlands

The focus of this report

Since 2000 over 250 community groups have taken part in one or other of the Centre for Ethnicity and Health's Community Engagement Programmes.

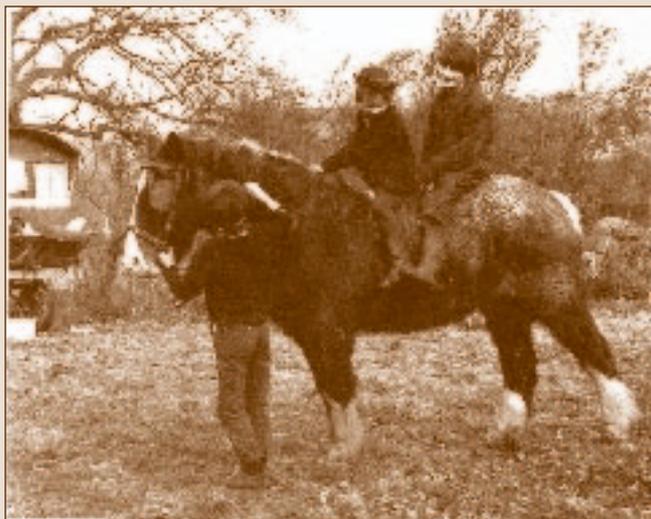
National Institute for Mental Health in England Community Engagement Programme:

Derbyshire Gypsy Liaison Group were one of 80 community groups who took part in the National Institute for Mental Health in England's Community Engagement Programme as part of Delivering Race Equality between 2005 and 2008. The objectives of the programme were to deliver improved equality of access, experience and outcomes for Black and minority ethnic mental health service users by:

- building capacity in the non-statutory sector
- encouraging the engagement of Black and minority ethnic communities in the commissioning process
- ensuring a better understanding by the statutory sector of the innovative approaches that are used in the non-statutory sector
- involving Black and minority ethnic communities in identifying needs and in the design and delivery of more appropriate, effective and responsive services
- ensuring greater community participation in, and ownership of, mental health services
- allowing local populations to influence the way services are planned and delivered
- contributing to workforce development, and specifically the recruitment of 500 Community Development Workers.

The focus of D.G.L.G.'s work was the emotional well-being needs of Gypsies and Irish Travellers. The objective of the study was to ascertain whether there are problems when members of the Travelling community find themselves in bricks and mortar. It may be possible that the culture shock of moving into a house may have consequences on a mental level and we wanted to find out exactly what this was. The aim is to show that delivering race equality in mental health care in this case may be linked to the accommodation needs of Gypsies and Travellers.

Project Team



Derbyshire Gypsy Liaison Group and members from East Midlands Gypsy and Traveller Forum. Community volunteers who worked on the report.

Muzelley McCready

Leicestershire

Muzelley took up post of CDW last year and is working towards training agencies with the Your Health is Your Wealth Pack. Zelli has worked on a number of projects with DGLG and worked in a voluntary capacity for a number of years before she took up post as CDW

Bridie Page

Derbyshire

Took up post of CDW with Muzelley on job share and works on the community packs for Your Health is Your Wealth. Bridie has worked on health promotion for a number of years and has illustrated for various publications for DGLG for example A Better Road culture booklet for health and other agencies in conjunction with Derbyshire County Council.

Ryalla Duffy

Lincolnshire

Volunteer to begin with DGLG now project manager of Lincolnshire Gypsy

Liaison Group, she has also worked in a voluntary capacity for a number of years

Ryalla has made videos of the Gypsy way of life and culture to raise awareness

Gary Harlington

Nottinghamshire

Gary is an invaluable volunteer to DGLG and also LGLG. He is willing to drop everything that he is doing and help out with events. It was beneficial to have Gary on the project and Gary has been a valuable driver and co worker on the project

Siobhan Spencer

Derbyshire

Coordinator to DGLG and works mainly on planning and accommodation issues.

Steering Group

Roger Kerry from North Derbyshire Voluntary Action

Angela Kerry from South Derbyshire Voluntary Sector Mental Health Network.

Invited to Steering Group also were Asha Day programme lead East Midlands and Nazreen Ahktar from **UCLAN**.

Our thanks



Our thanks go to Mr Tony Boxall for use of photos from his book *Gypsy Camera* these photos are copyrighted but we have express permission to use them for the report. Some people may criticise that we have used pictures from the early 1960's. in this report, but this was a time of transition for Gypsy people and more importantly we have not contained any photograph or any reference to families that we may have interviewed. Therefore for confidentiality reasons we have not put in any recent photographs. Jim the father of this family asked to be buried with Tony's book shortly before he died and we dedicate this report to him and also to Arthur Bennum who passed away just three weeks after being transferred into bricks and mortar from his home at the side of the road.

Cover photograph by Eliza Smith and case study 1 photo Verity Holland from an exhibition called *Travelling Lives* which LGLG undertook with The Monitoring Group 2007.

Nathan Spencer for helping out with the IT and getting all the photos into the report. Naomi Hatch for assistance with analysis of results when the graphs started disappearing!

Introduction (UCLan)

The Centre for Ethnicity and Health's Model of Community Engagement.

Background to the Community Engagement Model

We often hear the following words or phrases:

- Community consultation
- Community representation
- Community involvement/participation
- Community empowerment
- Community development
- Community engagement

Sometimes these terms are used inter-changeably, sometimes one term is used by different people to mean different things. The Centre for Ethnicity and Health has a very specific notion of community engagement. The Centre's model of community engagement evolved over several years as a result of its involvement in a number of projects. Perhaps the most important milestone however came in November 2000, when the Department of Health (DH) awarded a contract to what was then the Ethnicity and Health Unit at the University of Central Lancashire (UCLan) to administer and support a new grants initiative. The initiative aimed to get local Black and minority ethnic community groups across England to conduct their own needs assessments, in relation to drugs education, prevention, and treatment services.

The DH had two key things in mind when it commissioned the work; first, the DH wanted a number of reports to be produced that would highlight the mental health needs of a range of Black and minority ethnic communities. Second, and to an extent even more important, was the process by which this was to be done.

If all the DH had wanted was a needs assessment and a 'glossy report', they could have commissioned researchers and produced yet another set of reports that may have had little long-term impact. However this scheme was to be different. The DH was clear that it did not want researchers to go into the community, to do the work, and then to go away. It wanted local Black and minority ethnic communities to undertake the work themselves. These groups may not have known anything about mental health or anything about undertaking a needs assessment at the start of the project; however they would have proven access to the communities they were working with, the potential to be supported and trained, and the infrastructure to conduct such a piece of work. They would be able to use the nine-month process to learn about mental health issues, and how to undertake a needs assessment. They would be able to benefit and learn from the training and support that the Ethnicity and Health Unit would provide, and they would learn from actually managing and undertaking the work. In this way, at the end of the process, there would be a number of individuals left behind in the community who would have gained from undertaking this work. They would have learned about mental health, and learned about the needs of their communities, and they would be able to continue

to articulate those needs to their local service providers, or their local Drug Action Teams (DATs). It was out of this project that the Centre for Ethnicity and Health's model of community engagement was born.

The model has since been developed and refined, and has been applied to a number of areas of work. These include:

- Substance misuse
- Criminal justice system
- Policing
- Sexual health
- Mental health
- Regeneration
- Higher education
- Asylum seekers and refugees

New communities have also been brought into the programme: although Black and minority ethnic communities remain a focus to the work, the Centre has also worked with:

- Young people
- People with disabilities
- Service user groups
- Victims of domestic violence
- Gay, lesbian and bi-sexual and trans-gender people
- Women
- White deprived communities
- Rural communities

In addition to the DH, key partners have included the Home Office, the National Treatment Agency for Substance Misuse, the Healthcare Commission, the National Institute for Mental Health in England, the Greater London Authority, New Scotland Yard, Aimhigher and the Welsh Assembly.

The key ingredients of the model

There are four essential ingredients or building blocks to the UCLan Community Engagement model.

1. An issue about which communities and other key stakeholders such as commissioners and policy makers share some concern

The issue can be almost anything, but frequently involves a concern about inequitable access to, experience of, or outcome from, services. The community and other stakeholders may not agree about the causes of inequity or what to do about it – the key however is that they share a concern. Usually the concern will be framed within some kind of local, regional or national policy context (e.g. teenage pregnancy reduction).

2. The Community

According to the Centre for Ethnicity and Health model, a community engagement project must have the community at its very heart. In order to achieve this, it is essential to work through a host community organisation. This may be an existing community group, but it might also be necessary to set up a group for this specific purpose of conducting the community engagement research.

The key thing is that this host community organisation should have good links to the defined target community¹, such that it is able to recruit a number of people from the target community to take part in the project and to do the work (see section on task below).

It is important that the host community organisation is able to co-ordinate the work, and to provide an infra-structure (e.g. somewhere to meet; access to phones and computers; financial systems) for the day-to-day activities of the project. One of the first tasks that this host community organisation undertakes is to recruit a number of people from the target community to work on the project.

3. The Task or Tasks

The third key ingredient is the task or tasks that the community undertakes. According to the Centre for Ethnicity and Health model, this must be action oriented. It should be something that is meaningful, time limited and manageable. Nearly all of the community engagement projects have involved communities in undertaking a piece of research or a consultation exercise within their own communities. In some cases there has been an initial resistance to doing 'yet another piece of research', but this misses the point. As in the initial programme run on behalf of the DH, the process and its outcomes have equal importance. The task or activity is something around which lots of other things will happen over the lifetime of the project. Individuals will learn; awareness will be raised; stigma will be reduced; people will have opportunities to volunteer and gain qualifications; new partnerships will be formed; and new workers will enter the workforce. Besides, it is important not to lose sight of the fact that it will be the first time that these individuals have undertaken a research project.

4. Support and Guidance

The final ingredient, according to the Centre for Ethnicity and Health's model, is the provision of appropriate support and guidance. It is not expected that community groups offer their time and input for free. Typically a payment in the region of £15-20,000 will be made available to the host organisation. It is expected that the bulk of this money will be used to pay people from the target community as community researchers². A named member of staff from the community engagement team is allocated as a project support worker. This person will visit the project for at least half a day once a fortnight. It is their role to support and guide the host organisation and the researchers throughout the project. The University also provides a package of training, typically in the form of a series of accredited workshops.

¹ The target community may be defined in a number of ways - in many of the community engagement projects it has been defined by ethnicity. We have also worked with projects where it has been defined by some other criteria, such as age (e.g. young people); gender (e.g. women); sexuality (e.g. gay men); service users (e.g. users of drug services or mental health service users); geography (e.g. within a particular ward or estate) or by some other label that people can identify with (e.g. victims of domestic violence, sex workers).

² This is not always possible, for example, where potential participants are in receipt of state benefits and where to receive payment would leave the participant worse off.

The accredited workshops give participants in the project a chance to gain a University qualification whilst they undertake the work. The support workers will also assist the group to form an appropriate steering group to support the project³.

The steering group is an essential element of the project: it helps the community researchers to identify the community they are engaging with, and can also facilitate the long term sustainability of the projects recommendations and outcomes. The community researchers undertake a needs assessment or a consultation exercise. However the steering group will ensure that the work that the group undertakes sits with local priorities and strategies; also that there is a mechanism for picking up the findings and recommendations identified by the research. The steering group can also support individuals’ career development as they progress through the project.

The UCLan community engagement team

The Centre for Ethnicity and Health has a large and experienced community engagement team to support the work. The team comprises of two programme directors, senior support workers, support workers, teaching and learning staff, an administration team and a communications officer. They work across a range of community engagement areas of specialisation, within a tight regional framework.

National Programme Directors			
Northern Team	Midlands Team	Southern Team	Senior Programme Advisors
Senior Support Worker		Senior Support Worker	
Support Workers	Support Workers	Support Workers	Drug Interventions Programme
			Citizen Shaped Policing
Teaching And Learning Team			
Administration Team			
Communications Officer			

Programme outcomes

Each group involved in the Community Engagement Programmes is required to submit a report detailing the needs, issues or concerns of the community. The qualitative themes that emerge from the reports are often very powerful. Such information is key to commissioning and planning services for diverse and ‘hard to reach’ communities. Often new partnerships between statutory sector and hard to reach communities are formed as a direct result of community engagement projects.

In 2005/-6 the Substance Misuse Community Engagement Programme was externally evaluated. This concluded that:

- the Community Engagement Programme had made very significant contributions to increasing awareness of substance misuse and understanding of the substance misuse needs of the participating communities. It also raised awareness of the corresponding specialist services available and of the wider policy and strategy context.

³ Very often we will have helped groups to do this very early on in the process at the point at which they are applying to take part in the project.

- the Community Engagement Programme had enabled many new networks and professional relationships to be formed and that DATs appreciated the links they had made as a result of the programme (and the improvements in existing contacts) and stated their intentions to maintain those links.
- most commissioners reported that they had gained useful information, awareness and evidence about the nature and substance misuse service needs of the participating organisations.
- all DATs reported positive change in their relationship with the community organisations. They stated that the Community Engagement Programme reports would inform their plans for the development of appropriate services in the future.
- A significant number of the links established between DATs and community organisations as part of the Community Engagement Programme were made for the first time.
- The majority of community organisations reported their influence over commissioners had improved.
- Training and access to education was successful and widely appreciated. 379 people went through an accredited University education programme.
- A third of community organisations in the first tranche reported that new services had been developed as a result of the Community Engagement Programme.
- The vast majority of participants and stakeholders expressed high levels of satisfaction with the project.

The capacity building of the individuals and groups involved in the programme is often one of the key outcomes. Over 20% of those who are formally trained go on to find work in a related field.

- The views expressed in the report are those of the group that undertook the work, and are not necessarily those of the Centre for Ethnicity and Health at the University of Central Lancashire.

Executive Summary

The aim of this project was to find out if the community understand fully the broad spectrum of mental health issues? Did the community know where to go for specialist help and was the way they felt related to accommodation issues?

What started to be a basic questionnaire changed and became more like an in depth talk around the questions that we had in front of us, some of the questions families felt had no relevance but it was apparent that they **were** relevant as the discussion continued.

The overall comment for health services rate was good with both Irish Travellers and Romany Gypsies giving a 'good' to 'very good' response. 67 % of families felt that the health services that they knew about, were good and fair and there wasn't anyone who felt that they had been treated badly. 6% of Romany Gypsies felt their treatment was poor and 1% of Irish Travellers felt the same. However one of the graphs is misleading in that it shows that many families are registered with a Doctor - what it doesn't indicate is that a high proportion of Gypsy and Traveller families travel a significant number of miles to a Doctor with whom they are registered, which is usually a Doctor who knows them fairly well. This is very worrying in an emergency situation as an example of this was young man who was travelling from Derby to the other side of Birmingham after bad reaction to a prescription and a young woman who was in danger of miscarrying paying a taxi for a trip which was approximately 80 miles

On an unauthorised site where families have resided for 5 years they are still only allowed to register temporarily with the local Doctor.

We did not ask a specific question about receptionists but there were problems reported to us about reception staff at some Doctors clinics as opposed to not being satisfied with health worker staff.

On the whole families living in trailers had a better quality of emotional well-being although some were frustrated over the state of some sites.

For example one site, which is supposed to have a site licence, did not have adequate toilets and washing facilities, families were frustrated as opposed to depressed. Families waiting for planning permission had been brought to a depressed state either through a very lengthy application process to obtain planning permission and not be in the position of being on the side of the road or were on an unauthorised site but 'tolerated' by the local council, many families interviewed had gone through the planning application process more than once.

100% of respondents stated that the right sort of accommodation was important; many that had tried living in conventional housing had come back out on to the road again. There are varying reasons for this. Some families do not settle and cannot live a settled way of life, some cannot bear the thought of not being mobile and need to be on wheels. Some have the belief that ghosts reside in old buildings. Living away from their family was an important factor resulting in loneliness and isolation impacting on their mental health.

Historically some Gypsies and Travellers have settled well in housing but feel that access to their family was extremely important to them otherwise isolation became intolerable. 100% respondents were worried about children and the effects of the modern world on their traditions.

In terms of what help was needed to meet emotional needs 87% did not know what could be accessed and one woman answered

'probably tablets /pills and a social worker'

This is one example of the narrow remit of thought. This woman feels cooped up and caged in and is suffering from depression, she moved into a house 2 years ago as there are not enough available sites for families to go to.

81% of Romany Gypsy people will just access care through Doctor.

10% did not know of any other services to aid health.

6% had never sought any care in their lives.

1% used home care (there was interest in this but no knowledge of accessing).

51% have used and will use the A&E departments for general access for health.

Only 3% had used counselling service.

96% of Irish Travellers will access any care through Doctor.

84% have used and will use the A&E departments for general access for health.

20% have used the Traveller Education service as a point to gain help with health issues.

Not many people had actually accessed specific mental health services and did not have any information about this aspect of health.

Talking to older people we expected for many to be melancholy as that is often something across the board no matter what culture you are from. Elders as a general rule are wistful for the old days. However the younger generation were just as melancholy.

There needs to be more thought around accommodation that is more culturally appropriate for the elderly. Elder people in their 70s and 80s should not be worried about where they end their days, this is overlooked. We do have elder people even though the rate of life expectancy differs by 10 years in women and 12 years in men when in comparison with settled population.

It was a revelation to talk to the younger generation, comments are worrying that at the tender age of 18 they feel lonely, or that they felt they lost their way (after trying living in a house) and yearn for change. There were quite a high number of young community members that we interviewed.

Younger Travellers who were living in houses were isolated and felt lonely. Cultural practices are such that many children do not carry on to secondary school as parents fear that they will pick up bad practices, there is a very low uptake of further education and traditionally youngsters marry early compared to settled population.

A large number of young community members 29% were interviewed under the age of 25 and 90% of this number had young families of their own. The needs of the communities have to be addressed and quickly otherwise there will be further shortfall of legal bases before the backlog we have now is cleared approx. 4,000 families nationwide do not have a legal base and the evidence of family growth has implications on the numbers of legal stopping-bases needed for future development.

All the families interviewed that had children in houses, 42% were worried about their children growing up isolated from other Gypsies and felt that schools - especially secondary schools - do not understand that Gypsy people are extremely strict about certain aspects of education and children are not allowed to take part in sex education lessons or Personal and Social Education lessons. Romany Gypsies feel that this is an affront to culture. Many Irish Traveller families prefer Catholic schools and the older form of Catholicism is important to some of them. Young women are not allowed to go out drinking from both communities or be out at all times of night unaccompanied without an elder chaperone.

Families who had gone through the planning application system, some of them more than twice, said that this was the most stressful time of their lives. This can be further compounded by only receiving temporary permission from the Local Planning Authority after years of struggle to get the decision. 71% felt that their lives had been impacted on by this, considering the young number of respondents, these are not of an age to be able to afford land of their own, similarly the elder age group are also in that position.

Not all Gypsy and Traveller people are unhappy in housing and a small proportion 34% did adapt. However, their overall happiness and well-being was dependant on them being in close contact with family or other Gypsy/Traveller people and it was reported back to us by respondents that services do not know much about the community, some Gypsies and Travellers are secretive about their identity and the isolation that these families feel is very difficult for them.

National Recommendations

- It should be recognised that for the Traditional Romany Gypsy and Traveller communities it is part of their ethnic and cultural identity to have their homes on wheels. Whether they are moving everyday or not is immaterial but their aspiration is to be always mobile. It is in the mindset of the community to live close to family and friends and this should be recognised with culturally appropriate accommodation planned within the local authority/social housing planning system as a matter of course. This could be recognised if the planning definition of “gypsy” be linked to the Mandla criteria definition of Gypsy. This would ensure that these very small minorities would be protected under the law.

The Office for National Statistics should establish two separate categories for the 2011 Census i.e. one for Gypsies and one for Irish Travellers.

Local, Regional and National Implications

- Service providers need to understand the difficulties of access to Primary Care and re-assess the situation around the registration of patients as temporary, or form some kind of link scheme between a trusted Doctor of Gypsy and Traveller families and Doctors whilst families are travelling so that access for the families are improved and this will also ensure that families will not be using the A&E departments for general requests.
- Patient held record cards would be invaluable for the above recommendation; however there has been a reluctance to have these schemes (DGLG brought in a card in 1989 after the work on the health survey) but there is a reluctance to adopt by some Doctors who have an issue of health records lying around. Children, including Secondary school age now have the ‘Red Book’, which provides a health record. It may be that records on a swipe type card would be advantageous for keeping the health records up to date and being in touch with varying clinics.

Create and Improve on Resources by:

- Develop a training pack for health agencies to inform about cultural aspects of life of Romany Gypsies and Irish Travellers. This must be in conjunction with agencies with specialist knowledge and who have the community’s confidence and trust. A collaborative way of working would be to involve key influential individuals from this community.
- Develop in collaboration a community resource pack in a variety of formats, not just written format, on health information. This should include information for support to those who are suffering upset emotionally.

These recommendations tie in to the following recommendations of the Delivering Race Equality in Mental Health Care (2005)

- Less fear of mental health care and services among BME communities and BME service users.
- Increased satisfaction with services.
- A more balanced range of effective therapies such as peer support services, psychotherapeutic and counselling treatments, as well as pharmacological interventions which are culturally appropriate and effective.
- A more active role for BME communities and BME service users in the training of professionals, in the development of mental health policy, and in the planning and provision of services; and
- A workforce and organisation capable of delivering appropriate and responsive mental health services to BME communities.

Background Information



There has been very little study undertaken regarding the emotional health needs of Gypsy and Traditional Traveller people.

The Health status of Gypsies and Travellers in England 2004 - a study by Sheffield University. Its conclusions in relation to mental health needs were:

- Only 3% have accessed specific services for mental health.
- There is more trust in family carers rather than in professional care.
- Accommodation was the overriding factor, mentioned by every respondent in the context of health effects.

Other relevant statistics (recently reiterated in the Government Task force on Site provision) The Road Ahead 2007 :

are

- Around a quarter of families living in caravans still have no authorised pitches.
- The life expectancy of Gypsies and Travellers is approximately 10 years less than the national average.
- 17% Gypsy and Traveller mothers have experienced the death of a child compared to less than 1 per cent of the wider population.
- More than 40 per cent report long-term illness compared to 18 per cent of the settled community.
- In education, 16 % of Irish Traveller children, and 14 % of Gypsy children achieved five A*-C grades at GCSE, compared to 59 % of children overall.

A study by Wrexham Local Health Board and Helen Lewis, Cardiff University (2006). Data collected on 81 mainly Irish Traveller participants.

- 15 (18.5%) said they that were suffering from some mental health problems.
- 24 (29.6%) said that they were on anti-depressant medication.

Recently (2007) Bristol Mind published a survey on the Traveller community, which found that the community did not want anything special, just understanding.

We wanted to undertake a wider study over a wider area.

Accommodation complications

The planning law around Gypsy & Traveller applications is complicated and compounded by “gypsy” status in planning law, which strikes at the ethnic identity of Gypsy people. Despite the new planning guidance 2006 Planning for Gypsy and Traveller Sites¹ there are still cases that have refused sites on the basis that the individual is not travelling for the purposes of making a living so, therefore, has lost their status to be a ‘gypsy’ within planning law. Our study will see whether our participants have encountered any complications with regards to the planning system.

Romany Gypsy and Irish Travellers as two races are recognised under the Race Relations Act as defined by the Mandla criteria² Irish Travellers received recognition in 2000 under the Mandla criteria.

Romany Gypsies originate from India whilst Irish Travellers are an indigenous group to Ireland. Therefore there are differing beliefs and traditions.

The Housing Amendment Act 2004 stipulates by law that all District and Borough Councils should undertake an assessment of need for any Gypsy and Traveller people in their area, including the Showmen who are not recognised as an ethnic group but they are a cultural group with a long, shared history.

Some regions have tried hard to carry out the assessments in a thorough way, but there have been some problems with them because of lack of knowledge of the interviewees. This is further compounded by numbers of pitches being reduced if it is felt that the numbers are too high.

The best advice is to involve the Gypsy or Traveller community and to encourage the groups or other community members to carry out the interviews themselves.

Please see Reference for Planning definition ¹ and Mandla criteria ²

One of the Government’s responses to the Final Report of the Independent Task Group on Site Provision and Enforcement for Gypsies and Travellers (April 2008) was

“Ministers should meet Gypsy and Traveller representatives to discuss their concerns about the different definitions used for Gypsies and Travellers for planning and housing purposes. Government time should also be set aside in the House of Commons to debate this issue openly.”

The Department of Health recognises the importance of the Pacesetters programme in trialling innovative approaches to some of the more deep-seated health access problems experienced by Gypsies and Travellers. Further work will follow the completion of trials in six Strategic Health Authorities. The Department of Health will ensure that the lessons from the trial period, as well as

examples of good practice, are disseminated widely to the NHS. Other recommendations are as follows

"The Department of Health should ensure that good practice emerging from its Pacesetters programme is disseminated widely amongst health practitioners."

"The Office for National Statistics should ensure that two separate categories are included in the 2011 Census for Gypsies and Irish Travellers."

(Government Response to The Road Ahead 2008)

What did we want to do, why and how we went about it



What did we want to do?

Derbyshire Gypsy Liaison Group wanted to evaluate how individuals were feeling in regard to their emotional health and well-being and how they felt in themselves with regard to their accommodation and also by undertaking this find out:

- Does the community understand fully the broad spectrum of mental health issues?
- Does the community know where to go for specialist help?

And

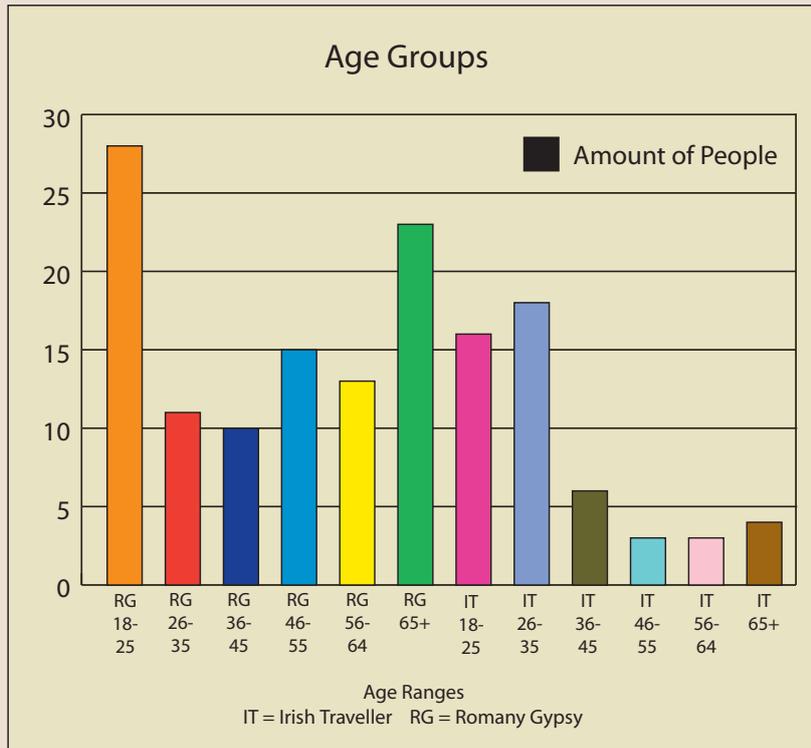
- Was the way they felt related to accommodation issues?

Why did we want to do it?

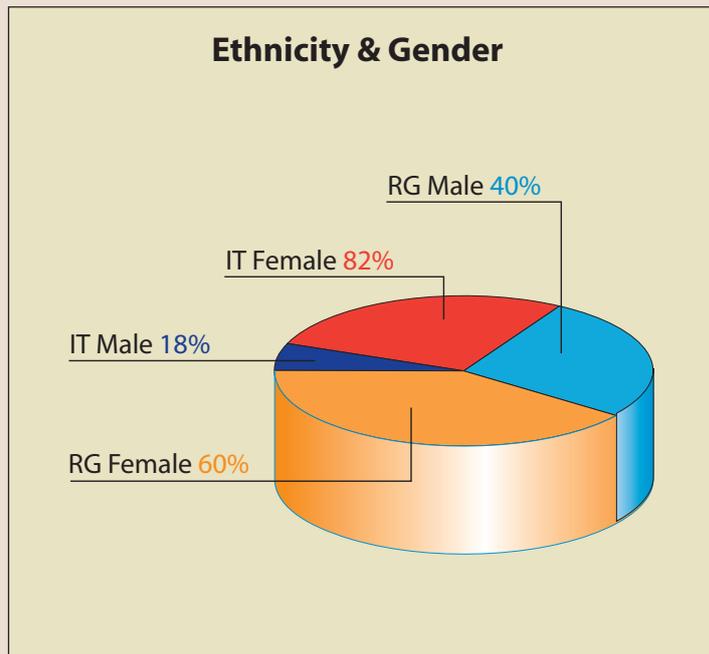
Certainly it wasn't because we don't have enough work to do! Mainly it has been that over the past 20 years DGLG has undertaken a lot of accommodation work with Gypsy and Traveller people and evidence started piling in as to how stressed some members of the community were ending up for a variety of reasons. We wanted to address this and if we can produce an independent report that can help inform agencies and assist policy change at Local and Central Government level it will be beneficial.

The promotion of health (and prevention of a long and costly road, that neither Gypsy, Traveller or Agency wants to go down,) is a more beneficial option. This report might assist the policy decision makers.

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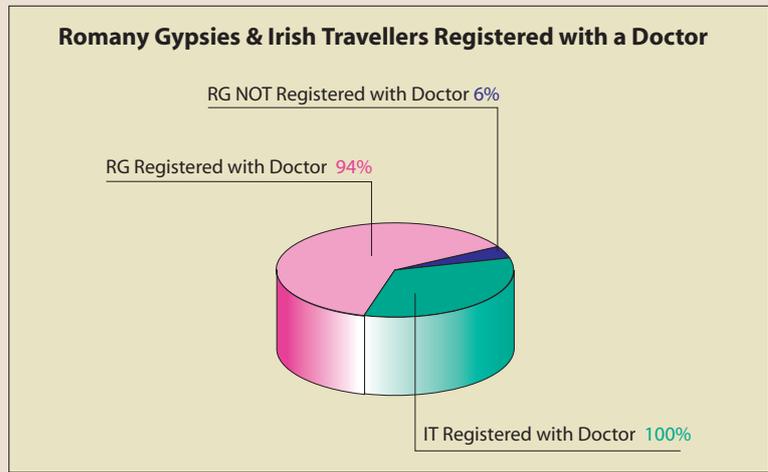
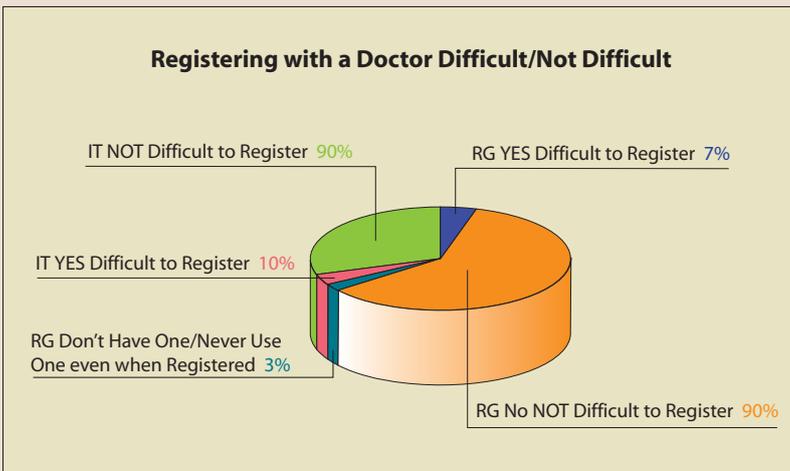
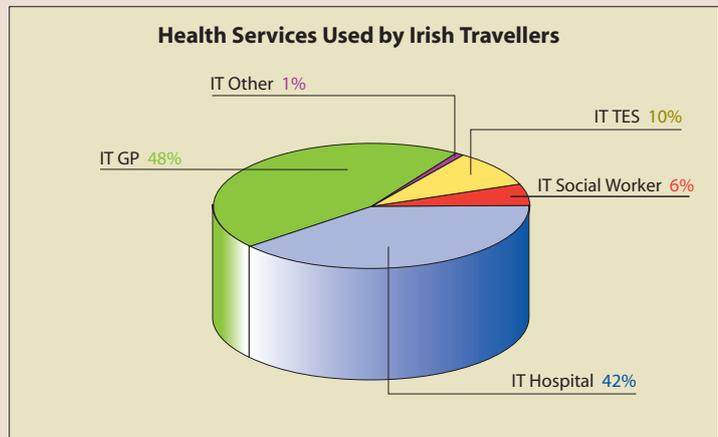
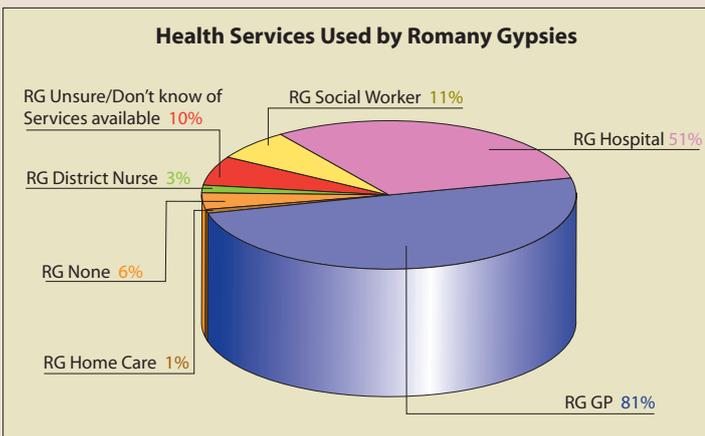


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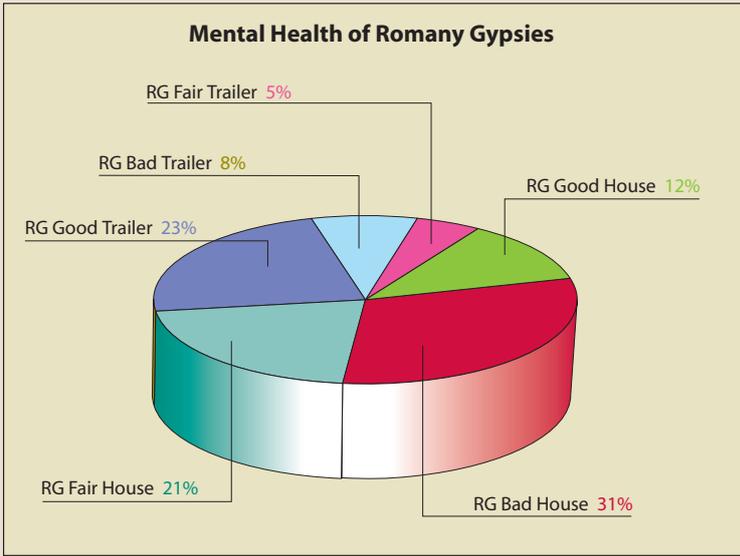


Out of the **50** Irish Travellers interviewed **19** were born in Southern Ireland. All followed Roman Catholic religion

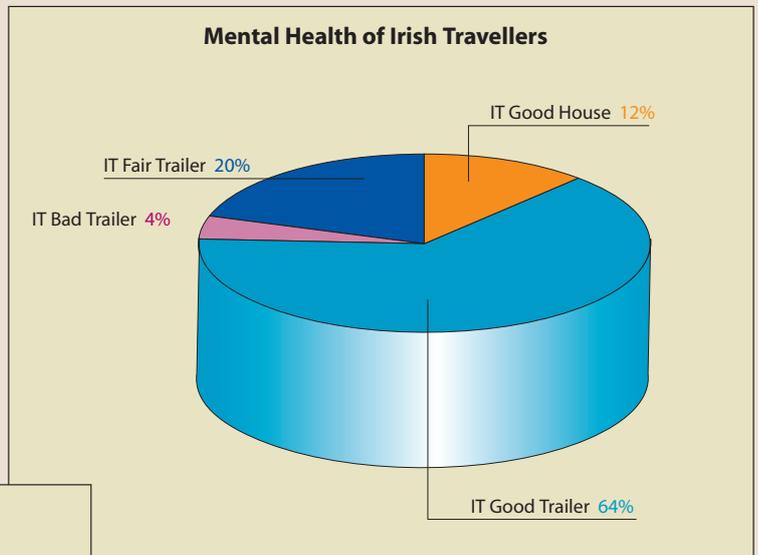
All **100** Romany Gypsies were born in UK following varying Christian denominations, including Catholic and Born Again Evangelists. A proportion did not like to answer as felt that religion is a private matter 20%

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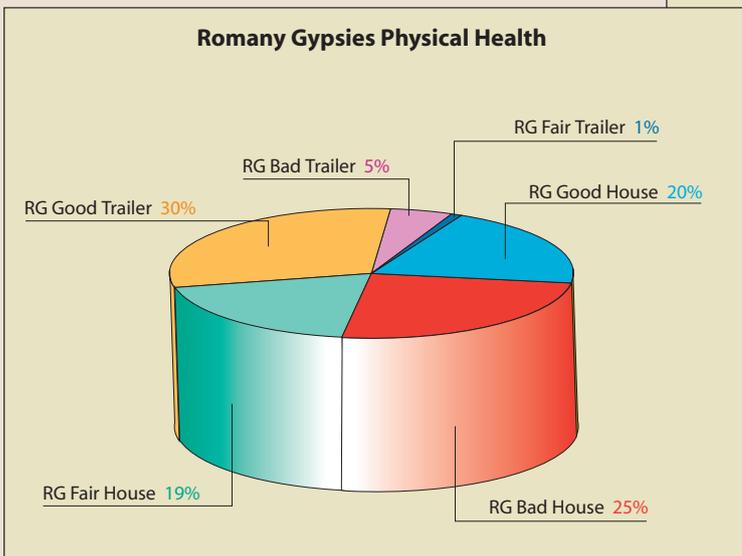
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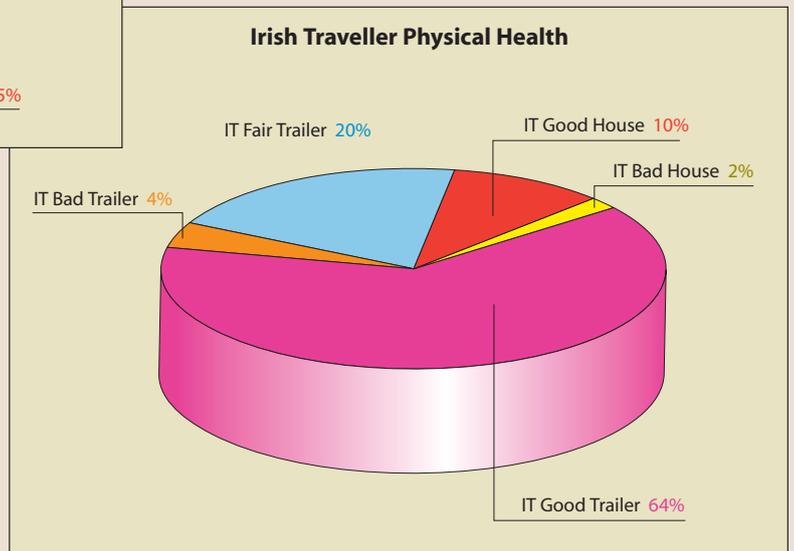
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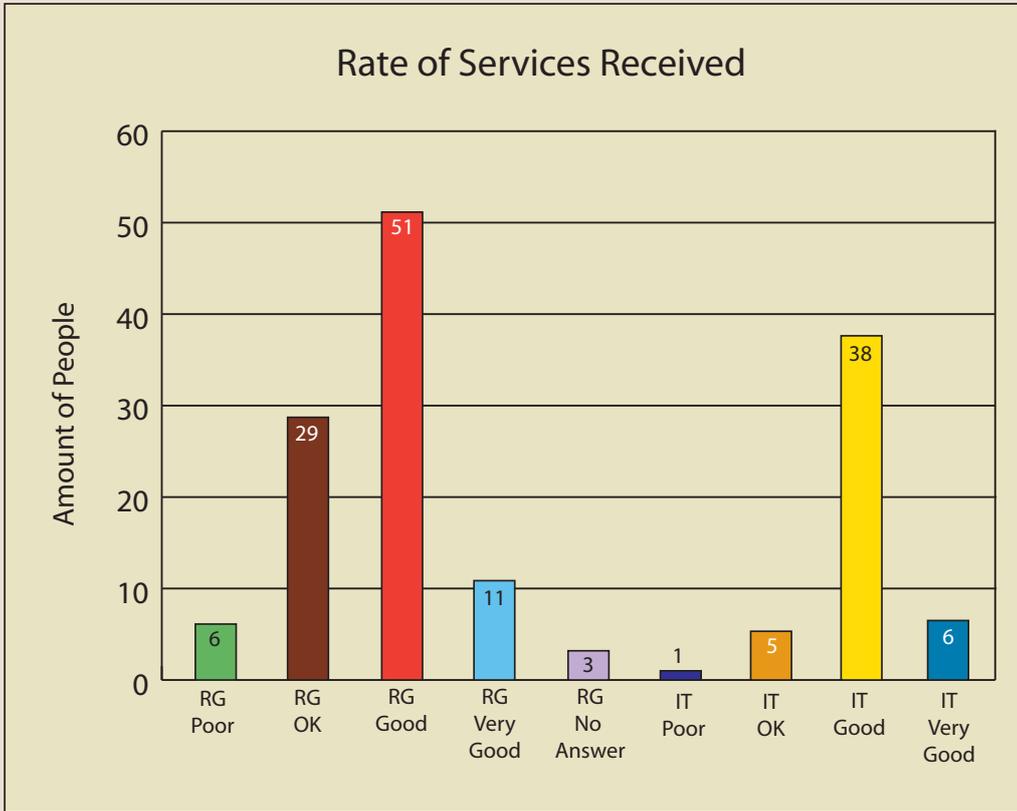
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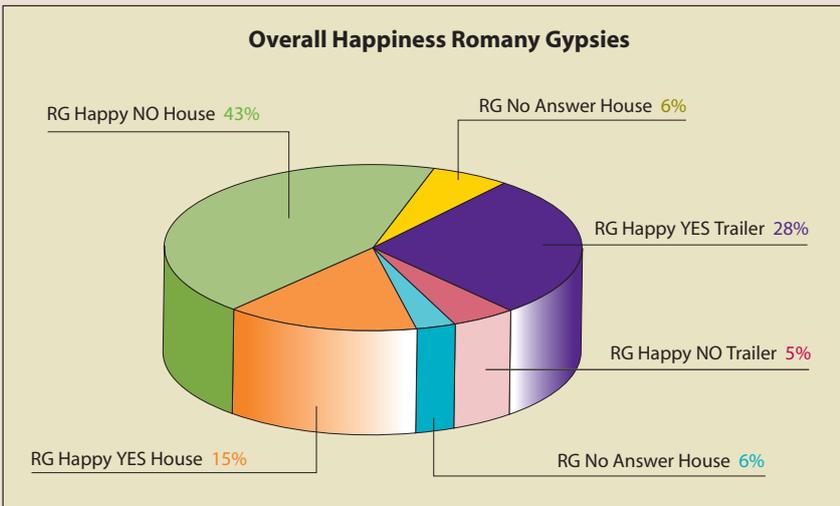
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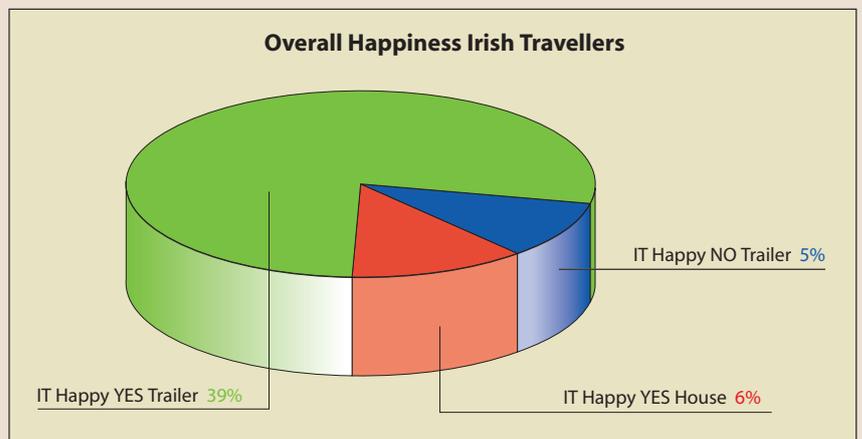
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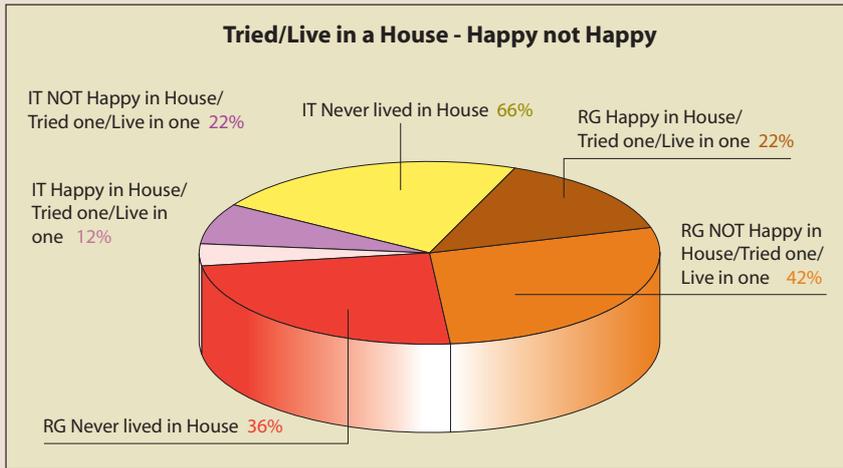
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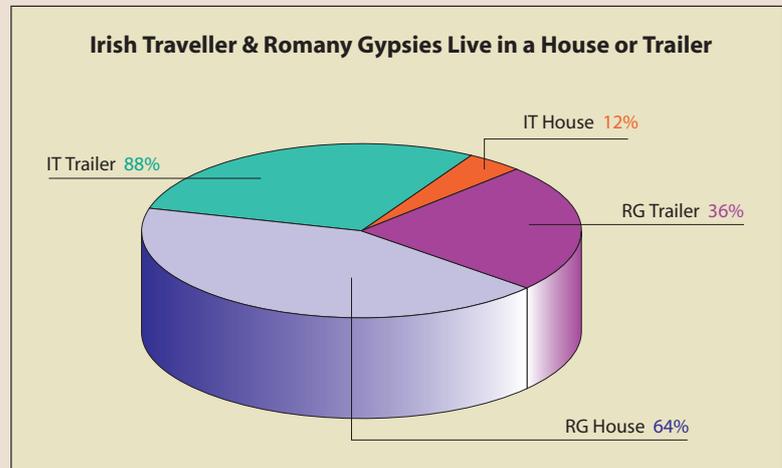
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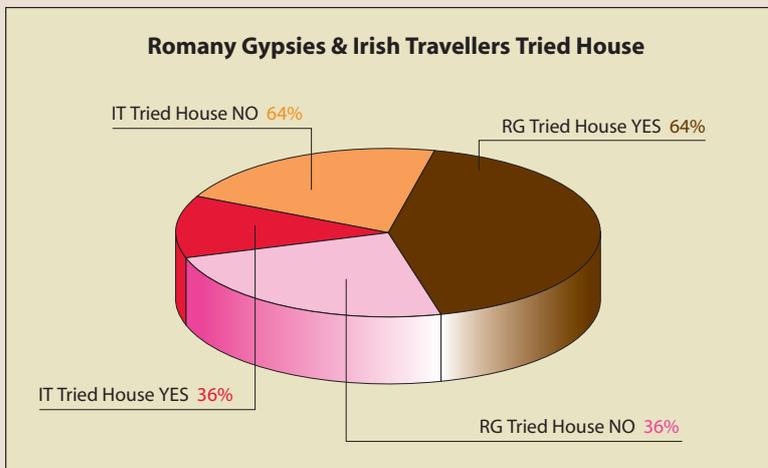
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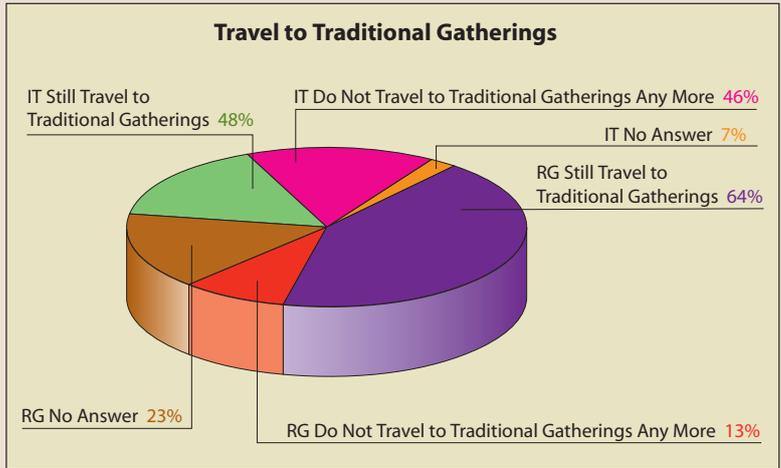
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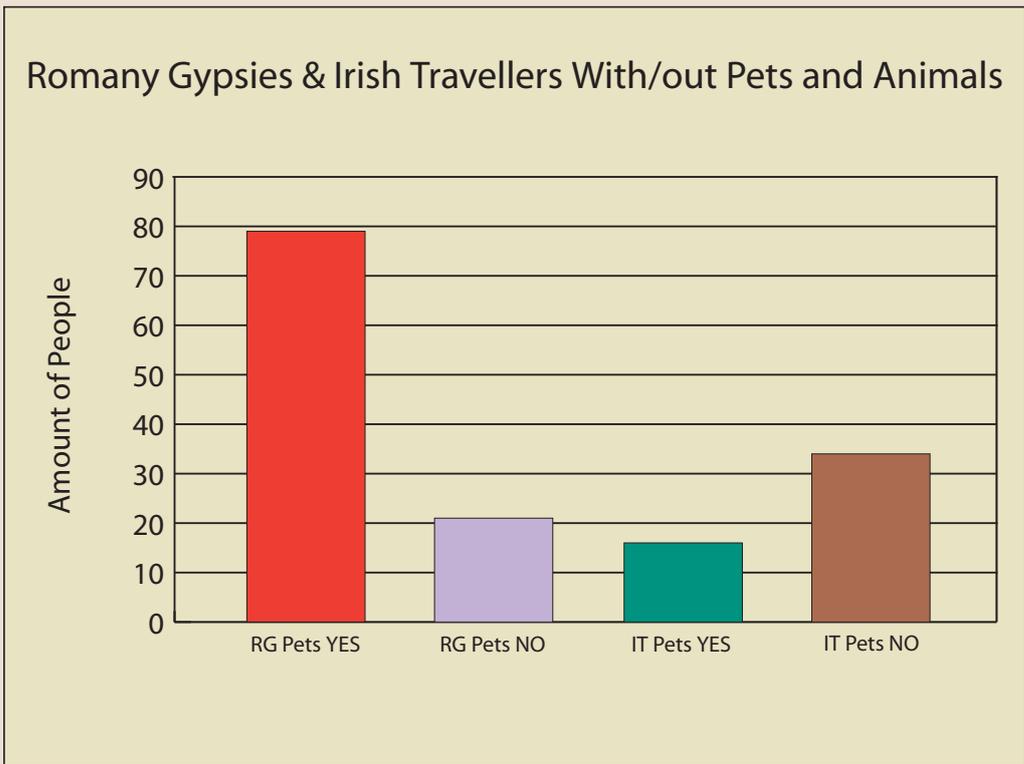
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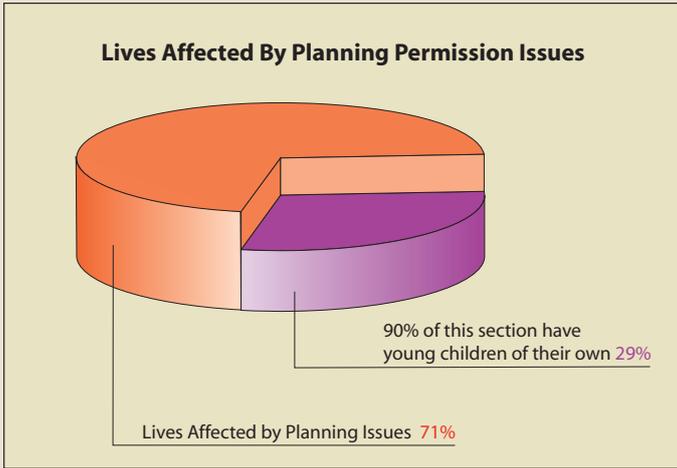
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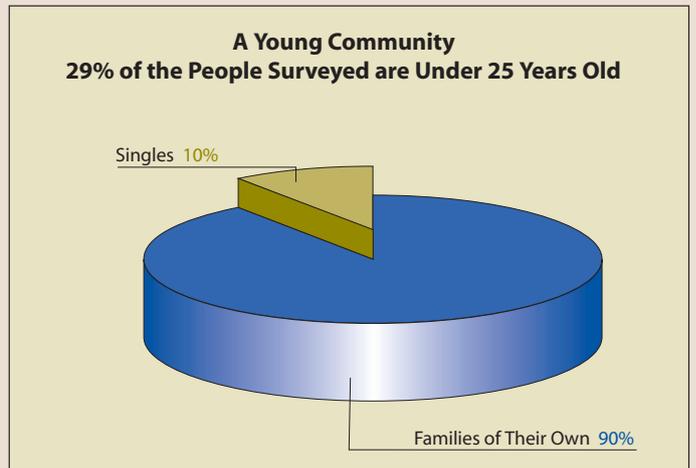
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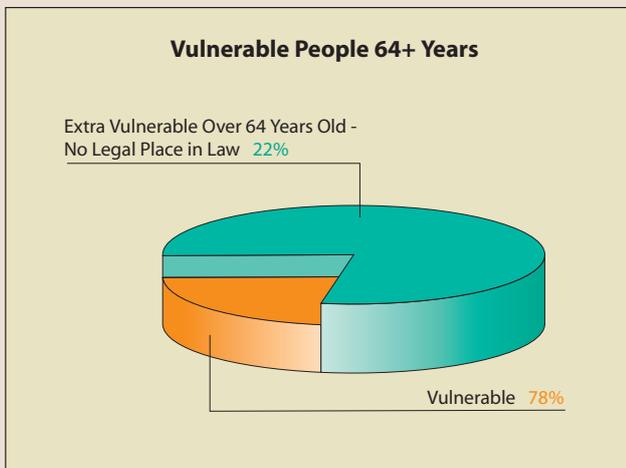
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U



How we went about it

We recruited volunteers to undertake the work over the region.

We contacted families that were known to us who might be interested in the survey.

The volunteers were supported by Uclan, with a series of workshops that were held during the study period which included how to present study findings.

4 Members signed up to gain a University Certificate in Community Research and Mental Health certificate.

We were pleased that our members received a qualification through the university.

We sampled 150 questionnaires across the East Midlands region.

We ensured that the correct ethics procedure was carried out and DGLG workers and volunteers are CRB checked as a matter of course.

All data was securely locked away and we assured the families that we would not divulge this to a third party.

DGLG is registered with Supporting People accreditation and is aware of the ethical issues around vulnerable people including those with mental health needs.

We set up a steering group to oversee the questionnaire with DGLG coordinator. Derbyshire Primary Care Trust has recently funded DGLG for Community Development Work and we have two based at DGLG on job share. South Derbyshire Mental Health Forum and their counterpart in the North of the county came on the steering group to help formulate the questionnaire. CDWs accompanied volunteers to undertake the research. Our CDWs are from the community and this project helped to capacity build them also.

We advised the community of what we wanted to do by DGLG meetings and mail out.

Sent out a leaflet with our phone number on to families and also had the information at DGLG meetings.

Phoned families that we were in contact with both in housing and on the road.

The survey was taken over the winter months so that enabled us to get a good mix of respondents. We needed people in trailers, people who had tried housing and come back out and those that had stayed in housing.

We feel that we did get a good mix by the quantity of questionnaires that we finally received. However because of various needs assessments it was difficult to obtain interviews as many families felt consulted to death, and many had the opinion that there is a lot of talk and no action, because the people knew us and that we were looking at the issues in a different way helped.

We did not hold focus group meetings, as most of the community prefer one to one discussion.

There are extensive quotes in the report, as this is the finest way we feel to carry the message forward. Some who sat with a questionnaire did not want to bother with some of the questions. They felt that some of the questions on mental health were just not applicable, but talked just on how they, felt. This, we thought, was very applicable.

Many felt that they had been consulted to death just recently with the Assessments of Needs that is now a requirement under amendments on the Housing Act 2004 and has been undertaken over the East Midlands region in the last eighteen months.

We made a concentrated effort to case study men also, as it is often the case that men were out working in the day. Their views were important to present a fair account. As we wanted to undertake a qualitative study as opposed to tick box. We made notes of all interviews word for word

We have a mix of in-depth study and basic quantitative data. We produced some of the findings as graphs and we have not changed the words that were spoken to us.

The question asked by the community was “will this consultation process deliver sites?” We could not answer that.

List of Graphs

- A. Age Groups**
- B. Ethnicity/Gender**
- C. Registered with a Doctor**
- D. Difficulties with registration**
- E. Health services used by Irish Travellers**
- F. Health services used by Romany Gypsies**
- G. Mental health of Romany Gypsies**
- H. Mental health of Irish Travellers**
- I. Physical health of Romany Gypsies**
- J. Physical health of Irish Travellers**
- K. Rate of services used**
- L. Overall happiness of Romany Gypsies**
- M. Overall happiness of Irish Travellers**
- N. Tried house happy/not happy**
- O. House or Trailer at this moment in time**
- P. Overall numbers that had tried house**
- Q. Travel to traditional Gatherings**
- R. Animals**
- S. Planning has caused difficulties**
- T. a Young Community**
- U. Vulnerable Age Group**

A. Age Groups

B. Ethnicity/Gender

We were extremely pleased with the variety of ages that we were able to interview. It was a coincidence that the figure was split two-thirds Romany Gypsy to one-third Irish Traveller. This is comparable to national statistics. It shows a lot of young families. Information in graph Q also needs comparing with this one as we had a number of interviewees that were elderly and this was the main reason behind those that answered that they no longer travelled to traditional fairs.

C. Registered with a Doctor.

D. Difficulties with registration

Note C+D graphs show the importance of talking rather than just ticking boxes as discussion with families revealed that actually many families who stated that they were registered with a Doctor were actually registered with one that they trusted some distance away.

The graph showing quite a high proportion of families registered is not quite a true accuracy of the real picture. Many families are registered, but it is not a local Doctor that they are with. The implications of this could be quite bad during an emergency.

The majority of the community were satisfied with their treatment from the health services but some Irish Traveller families reported problems with some surgery receptionists not allowing them access to a Doctor.

There was very little reply to knowledge of mental health services and many had not accessed services.

Tablets and drink were mentioned, most families were not aware of other alternative therapies available via their GP. Only three respondents mentioned counselling at a time of trauma in their lives.

Answers we got to the question 'what does mental health mean' did not take in the broad spectrum of stress/worry to total breakdown.

E. Health services used by Irish Travellers

Note Traveller Education service (TES) although not a health provider was used to access help in gaining services by 10 families.

F. Health services used by Romany Gypsies

Note 10% Of Romany Gypsies did not know of other services available.

However there was an improvement of agencies working with families compared to research we undertook in 1989, more families are actively using agencies but there is definitely a lack of knowledge on accessing alternative help for stress rather than medication. Both groups did not have any information about access to mental health services.

G Mental health of Romany Gypsies

H. Mental health of Irish Travellers

I. Physical health of Romany Gypsies

J. Physical health of Irish Travellers

Physical and mental health overall was better for families in trailers, there was a high number of elder people that we interviewed (23 over age of 65) that had ended up in housing due to old age and deteriorating health, so for those elderly people they were happier to have water from a tap, however some felt isolated. Those elderly ones that did not have a secure base for their home and were still in trailers were actually at the age range of mid-70s to 80s. They were happier mentally and physically but worried over what was going to happen in the future.

For the families in trailers that showed depression, this was due to either waiting for planning system decision, decision over eviction, or complications due to planning accommodation issues.

For the Irish Travellers it was the condition of sites and the lack of security that caused the stress. Families that had been allowed to stop in various locations across the region were worried over the lack of clarity and the forthcoming decisions, which might mean they would have to break the support that they were getting from clinics and schools.

We picked up a couple of severe physical issues through the study regarding families struggling to look after elder people with little support and no knowledge of what is available for those families. There is still a fear that social workers 'might take someone away'.

K. Rate of services used

Note Only a small number fed back dissatisfaction with the NHS as a whole 6% of Romany Gypsies and 0.5% of Irish Travellers.

L. Overall happiness of Romany Gypsies.

M. Overall happiness of Irish Travellers.

N. Tried house happy/not happy.

O. House or Trailer at this moment in time.

P. Overall numbers that had tried house.

Approx one third of Romany Gypsies interviewed had never tried housing and found the whole concept harrowing. Of the two thirds that had tried housing about one third had come back out. The families that were happy in housing were so because family were in close proximity. Of the two thirds that are left only 15% stated that they are happy. Some would only opt for housing at times of illness and some stated that there ought to be more thought about elder peoples needs when not well enough to travel but not wanting to go into bricks and mortar.

Regardless of what happens in life both Romany Gypsy and Irish Travellers were very philosophical and most days interviewing was a laugh a minute. Regardless of some of the history and quotes that we have compiled in the report.

Q. Travel to traditional Gatherings.

Most families still travel taken in conjunction with graph A above it is easy to see that that it is the elder ones that cannot now travel that are not going to the fairs.

R. Animals.

As quotes.

We have used individuals answers on a word for word basis and hope that time will be taken in reading what they have to say.

S. Planning had affected 71% of lives The 29% were quite a young community under 25.

T. 29% of the overall community were under age of 25 - 90% of this group had young children of their own.

U. Of the elder people we interviewed 4% over the age of 65 did not have a legal base.

Case study 1 - Belief System



The Muller Mush. (Romany Gypsy)

The belief in the Muller Mush³ is very strong especially within the generation who lost their traditional stopping places in the early sixties and were cleared off the common grounds, families from Shave Green in the New Forest for example. This generation found themselves forced into bricks and mortar accommodation and stress took its toll and the natural belief that bricks and mortar housing may have a ghost in it that has not been put to rest. It can be a belief for some that manifests itself very strongly, and the situation can be amended by laying ghosts to rest or families understanding the knowledge of where they are living, and who was in the house before. Or the family just have to move.

This belief can be very real to the person involved. It can manifest itself into a psychosis that the medical profession may not fully understand, so it's not talked about. It is linked to the belief that personal belongings of the deceased person are burnt, including the caravan. Otherwise the spirit lingers in this world.

This belief is similar to the belief of the Wendigo amongst some Native American people. Many families now who follow the Evangelist path are keen not to promote this belief but it is still here with us in today's modern society.

Case study 2 - The cost of trying to adapt



Tried and tested, I won't do it again.

*"Well, I had problems on a Council run site with other Travellers and we made up our mind seeing that we had 3 of our 5 children still at home we would move into bricks and mortar. After a short time being on our own away from friends and family which we were not used to, I found myself in a distressed state. I went to the local Drs who gave me *****[prescribed drugs] for my nerves I did not settle in the 9 years that we were there and it made me worse that my three children were wed from there. During the 9 years I had two nervous breakdowns so we decided after all we would buy a trailer and move back to friends and family. Even though we have had our hard times and good times I am very happy to be back in my trailer with my own kind."*

67 yrs old Romany Gypsy.

Case study 3 - It is not only the elder generation that are wistful.



"We are only here because we've got no choice, my kids hate it because they haven't got any friends, I hate it because it's lonely. My husband spends very little time indoors with us because he doesn't like being closed in. The neighbours don't mix with us, but we don't really want them to. We saw lots of friends and relations every day when we were in the trailer, you don't feel like you're the only person in the world. I feel alright at the moment because its winter and the days are short so I don't have so much time to sit about thinking... but I am dreading the summer when we want to be on grass fields."

Young Romany Gypsy mother 29 yrs old.

"I have lived in a house. It's like I've lost the way"

Young Irish Traveller mother 24yrs old.

Why ask about animals?

Another word to describe Gypsy or Traveller people would be that they are both a nomadic people. In times gone by extended families that go from pasture to pasture with their animals and today like an inherited memory this carries on with the love of having animals around.

The majority of all the Romany Gypsy people interviewed could not imagine life without animals, Gypsy people tend to be more of a rural people, the few that did not have an animal was due to restrictions on where they lived.

The majority of Irish Travellers that we interviewed did not profess the same link to animals but this it could be down to the fact that many Irish Travellers interviewed have been forced to inner city areas and are in larger groups.

Dogs however were cited as being a necessity and an old Irish belief still held is that dogs warn you if a ghost is about. Many interviewed had relatives that kept horses but did not travel as much with animals.



'I need me animals round me, sometimes they make more sense than us humans! They make me happy' –

Romany Gypsy man 72 years old

"Not allowed to have pets or animals here"

Irish Traveller Man 35 years old



"He did cry when he had to let go of his hens he only had the six miniatures but its not allowed to have them on the site so his dad said that they had to go, he's only 3 or 4 so it was hard for him to lose his pets, I'm glad that we found somewhere for them he can visit them but its not quite the same is it?"

Romany Gypsy Grandmother.



"I want to have somewhere for my child to grow up safe somewhere I can have a shed with electric and toilets somewhere.... A little bit like some where over the rainbow isn't it???"

(Respondent laughing because she feels it's beyond reach.)



Not just sentiments from the older generation of a passing of life and culture but also from the younger respondents. There were many that expressed worry over what would become of their children and the isolation that some children find themselves in.

"I don't like the house I'm fed up of looking at it, I don't meet my own people, I don't see no one I don't mix with the other boys (gorgers®)."

18 yrs, Romany Gypsy boy.

Worries about school - Case study quotes



"I feel my kids are miles away from me I prefer everyone to be in the same room. I miss feeling the effects and the noise of the weather. I feel closed in and alone."

27 yr mother.

"I feel cooped up and lonely and feel worried about my children's happiness and well-being as they don't have any friends nearby to play with or come to their birthday parties I do not feel comfortable with letting my children play with other children around this area I am scared of them getting lost or hurt outside I have hardly any social life and find it hard to keep myself busy."

29yr old mother.

"The youngsters get into bad ways, they teach them bad things in school so we don't send them to the big school. What's the good of teaching them about things that they shouldn't be getting up to at 13 or 14, no we don't allow it. Its worse in a house, you have to make an effort to make sure they are seeing their own."

38 yr old mother.

In our own words

What is your understanding of the words mental health?

"Its like a flower, do you know what I mean its like a flower that's wilted and needs water, the mind is like that it wilts if it doesn't have company you have to feed it with company."

Romany Gypsy woman, over 70 yrs.

"It's what your mind tells you when you get up in the morning if you're happy and that."

Irish Traveller woman, 45 yrs.

"Someone who lives in Rampton you know, the local divvy kair³."

"When you can't look after yourself."

"Your brain is knackered."

Some did not equate taking tablets for nerves or drinking as a symptom of mental health needs. All gave reliance on family as a way of coping with times of stress.

Almost all the respondents said that Gypsy and Traveller people don't have mental health problems and that no help is needed but note following remarks.

"I do talk to my family about things and sometimes I'm on the drink."

Irish Traveller woman, 48yrs.

"I don't sleep at all when I worry about this and that, but that's life sometimes it is a worry, would be less of a worry if we had the ground passed. I can't stand this temporary thing it plays havoc you can't settle in your mind can you? Had to have sleeping tablets when it went up to the court."

Romany Gypsy woman 48yrs.

"I drink a lot of lager at night, I feel sad there is no room for me on mothers plot. I talk to her and she feels the same."

Romany Gypsy, 24yrs.

"I don't feel I have got any mental health issues but

I have terrible mood swings like a beng, sometimes a proper beng.³

*I am on ***** [prescribed drugs]*

I call them cobweb tablets it feels like you have cobwebs over your face when you take them."

Romany Gypsy, 54 yrs old.

Do you think accommodation plays an important part in your emotional well-being?

"I was born in a caravan until recently I have lived in a caravan all my life living in a house to me is like living in prison."

"I don't mind living in a house but I miss the trailer, I was brought up in one and am more used to it than a house. I was tired of getting shifted and I wanted to be left alone and have some peace."

"I have lived in a house, it's like I've lost the way"

"Can't sleep in one so can't live in one, rather sleep in the motor."

"I don't have a choice it's what I was born to; it's a part of me"

*"The Dr gave me***** [prescribed drugs], I talk to my mother but she feels the same sometimes."*

"I go to my brother-in-laws and see how he copes in a house and it helps me to decide where I want to be and where I really need to be which is in a trailer."

"Yes because it's your home, aint it? It's where you spend most of your time."

"I feel like I'm being forced to live in a way that I wasn't brought up in."

"I have lived in both, prefer trailer I'm used to that."

"I don't know whether it is important to mental health but I know it's important to your happiness!"

"I don't like the house I'm fed up of looking at it don't meet my own people I don't see no one I don't mix with the other boys (gorgers)"

"Waiting for the planning was pure torture, pure torture"

"I can't imagine life inside that's a prison lady you know you get sent down for doing wrong that's why you're put behind them walls, why would I choose it I'd be trashed^p of it, atrashed of it."

Romany Gypsy man 80 + yrs

A few families do settle in bricks and mortar accommodation but for some, this was dependent on other factors, was there family around for example.

"I have my house and I like my house but I miss my family."

"My sister is next door so I have someone to talk to and share the ups and downs."

"I prefer to live in a house I can get to the college."

Answers on the whole were melancholy although they had got used to bricks and mortar accommodation.

"I got used to it but I still go down to the camp."

"I feel my freedom is being eroded."

"I miss my people and culture."

Others did not

"I tried living in a house about 20 years ago, I won't try it again, I just went very low in myself. Its not the same no family around here, if I feel that I am getting a bit low and everyone does sometimes because that's life, I just go next door some one will be in.

Isolation in the house that was my problem you know the isolation that is what did me. I was given Prozac in the house. I think that affected me. It's hard to get off something like that and I still get them on prescription, it's only occasional that I need them now I am out of the house that's the main thing."

Irish Traveller, 56 yrs old.

How can the mental health service be improved to meet the needs of Gypsies and Travellers?

"I think mental health needs to be explained a lot more to Gypsies because I think that there is a stigma attached to mental health issues amongst Gypsies.

Sometimes you do need help we are lucky we have our families after that there is the Dr, but sometimes you do need more than that.

I am fortunate as I have my family around me."

No one expected or wanted any specialist services. They just wanted to be made aware of what services were available. The majority said that they would access this through their Doctor. Most respondents felt happy with the treatment that they had received from their surgery. This reflected the findings in the MIND research.

"Inform workers of our culture so that they understand our beliefs and ways, countrymen^s don't understand about our ways."

"I take food in to hospital for my uncle. He doesn't know where it's made or who prepares it, so he wouldn't eat it. (mochardi)"

"Maybe some information that we could have a phone number or something"



“4 chickens, 11 dogs and puppies 4 birds, magic, dogs, chickens and horses!

How many horses have I got? Dunno, quite a few - I **don't know how old I am**”

“I don’t know what they mean I was born a Gypsy and will stay a Gypsy a leopard can’t change its spots”



Life’s Road.

Why do you like caravan life, what is it about the life?

“It’s what you are used to...

I know when its raining

I like to hear the patter of the raindrops on the trailer roof...”

Dedicated to all those elders who wonder about a safe resting base and a safe place to be and to all the young families with that Gypsy/ Traveller ‘gene.’

Bibliography/References

The Health Status of Gypsies and Travellers in England. University of Sheffield Report to the Department of Health 2004. Patrice Van Cleemput

Coronary Heart Disease and Gypsies and Travellers: Redressing the Balance Gypsies' and Travellers' Mental Health Status 2006 by Janine Adkins, Wrexham Local Health Board and Helen Lewis, Cardiff University. A project that was supported by the Welsh Assembly Government's Inequality in Health Fund.

Bristol Mind survey 2007

The Road Ahead Task Group on Site Provision and Enforcement for Gypsies and Travellers 2007 Communities and Local Government

Government Response to The Road Ahead: The Final Report of the Independent Task Group on Site Provision and Enforcement for Gypsies and Travellers April 2008 Communities and Local Government

¹ Planning for Gypsy and Traveller Caravan Sites circular 01/2006 Page 6. Para 15. Definition

Persons of a nomadic habit of life whatever their race or origin, including such persons who on grounds only of their own or their family's dependents educational or health needs or old age have ceased to travel either temporary or permanently, but excluding members of an organised group of travelling show people or circus people travelling together as such.

Circular 01/2006(ODPM):Planning for Gypsy and Traveller Caravan Sites,
www.communities.gov.uk/publications/planningandbuilding/circularodpmplanning

(Showmen have their own circular and they are covered under the Housing Act 2004)

² Mandla criteria Definition of an ethnic group.

The Mandla Criteria, drawn up by the House of Lords after the case of Mandla v Lee relating to Sikhs in 1983, is now used as a legal definition of what constitutes an ethnic group. The criteria are as follows:

Essential Criteria:

A long shared history coupled with a conscious sense of distinctness.

A cultural tradition of its own including family and social customs often, but not necessarily, associated with religious observance.

Relevant Criteria:

A common geographical origin or small number of common ancestors.

A common language, not necessarily peculiar to that group.

A common literature, including folklore or oral traditions.

A common religion different from that of neighbouring groups.

The characteristic of being a minority or being oppressed by a dominant group within a large community.

Reports

Moving Base families moving through Derbyshire DGLG 1998

A Safe Place to Be. A report on elder and families with disability with no legal place to be DGLG 2002

Resources available list:

www.dglg.org

<http://www.olderpeoplesmentalhealth.csip.org.uk/mental-health-and-well-being-of-black-and-minority-ethnic-elders/gypsy-elders-resource.html>

www.nimhe.csip.org.uk

A Better Road An Information Booklet for Health Care & Other Professionals Derbyshire Gypsy Liaison Group. Reprint 2007

Health survey which produced leaflets on Heart disease Strokes, Diabetes and Children's Needs 1989. Updated 2006

Elders mental health leaflets:

Kokoro³ for Romany Gypsies

It's Buri to Tair³ for Irish Travellers West Midlands CSIP March 2008

Word translation Romany language³

Divvy kair	asylum	(literally stupid house)
Mullah Mush	ghost	(dead man)
Trashed		frightened
Beng		devil
Gorgers		non Romany Gypsies
Kokoro		alone
Mochardi or mockardi	very often mistranslated as meaning dirty. It means ritually unclean, people are not happy with something because of their beliefs.	

Example to wash tea cloths with underwear.

Soaking clothes in a pan meant for food.

Young woman stepping over a rope of a tethered horse.

Please refer to A Better Road Culture Booklet.

Irish Traveller Cant

Its buri to tair It's good to talk

Countrymen non- travellers (sometimes referred to as buffers)

Leaflet sent out

**Birthright - Your Accommodation...
Choice Or Enforced?**

**EMOTIONAL HEALTH AND WELLBEING OF
GYPSY/TRADITIONAL TRAVELLER PEOPLE...**

Have you or any of your family ended up in a house? Are you
happy or unhappy?

Want to take part in a survey of Gypsies/traditional Travellers
across the east midlands?



MOVING FORWARD DCLG

This could be important for the future provision of sites!
CONTACT 01629 583300

On the whole the leaflet informed the community what we were undertaking but we did not get a good uptake on it due to over “consultation syndrome.” We had to work very hard to find families to take part, as many felt that they do a lot of consultation exercises but feel it does no good to the situation that many find themselves in.



Report of the Community - Led Research Project Focussing on the Emotional Health and Well-being
Needs of Romany Gypsies and Irish Travellers
Derbyshire Gypsy Liaison Group
East Midlands Region

COMMUNITY ENGAGEMENT PROJECT: the NIMHE Mental Health Programme.

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