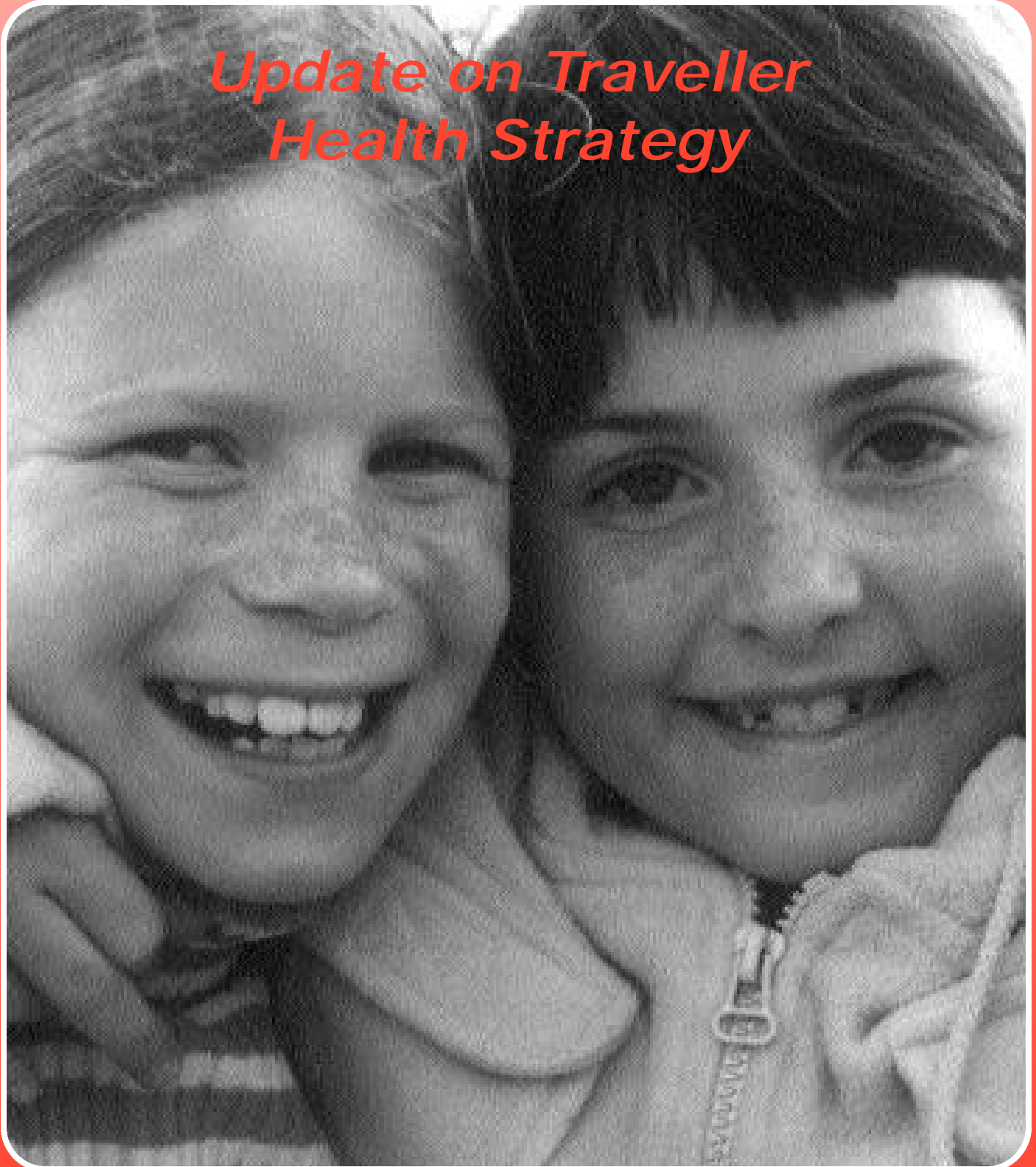
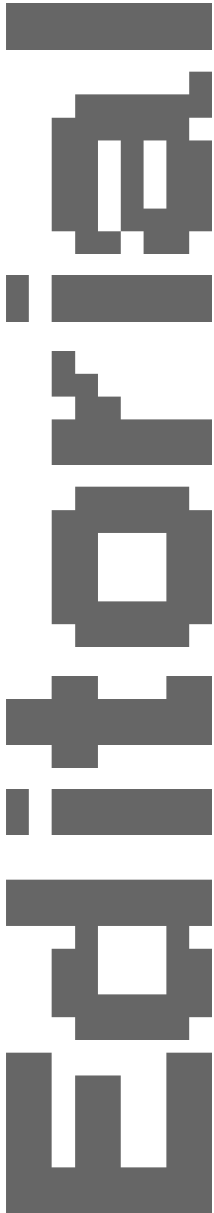


- COUSIN MARRIAGE NOT HARMFUL
- TRAVELLERS AS AN ETHNIC GROUP
- CENSUS 2001 - RESULTS



## *Update on Traveller Health Strategy*





In this issue of our Newsletter we concentrate on the work of the National Traveller Health Strategy (NTHS) at a national level to date. It is hoped this will prove a useful information tool for both Traveller organisations and for health professionals around the country. It also provides interesting examples of the apparatus necessary for engaging with Travellers and progressing Traveller issues and may provide useful insights for other statutory service providers.

The work of the NTHS provides, for example, the opportunity to develop a model to identify Travellers on health record systems in the context of their ethnicity. Once collected and collated this data can be disaggregated, allowing morbidity (sickness) and mortality (death) patterns for Travellers to be identified. This information will be critical to further planning of appropriate services for Travellers as it will identify the gaps and weakness in the system and facilitate the setting of targets to reduce morbidity and mortality.

This system once established on all record systems will allow the health boards to monitor the access, participation and outcome for Travellers to the services and will measure the impact of initiatives as outlined in the NTHS.

The NTHS also highlights the need for Travellers and Traveller organisations to be supported to participate at each level of Traveller health from primary health care projects at local level, to Traveller Health Units at regional level and to the Traveller Health Advisory Committee at National level.

In this context Pavee Point, as a national resourcing organisation has been given funding by the Department of Health and Children to support the Department in the implementation of the NTHS. Part of this remit included the production of the video on the NTHS and participation on the national Traveller health advisory group and all its sub-groups.

Pavee Point is directly involved in providing support and training to the 'Ethnic identifier sub-group' and the 'Traveller health status and needs assessment working group'. We feel very strongly that the only way to ensure implementation and sustainability of the NTHS, is to build up the Traveller and health board infrastructure and capacity at local and regional level.

Pavee Point is also resourcing the National Traveller Health Network (NTHN) which is a national network of Traveller organisations involved in health. Currently we are supporting the development of regional Traveller health networks to provide support, resource materials and training at local level on e.g. Trainers Training on primary health care; community needs assessment; anti-racism; culturally appropriate provision; preparation modules and materials for the Traveller needs assessment etc.

We are also providing support and training to THU on the NTHS; Travellers and Travellers health and working in partnership etc. Pavee Point is also in negotiations with FÁS national office and the Department of Health and Children to explore the possibility of a national standardised training programme and accreditation system for the Primary Health Care Projects.

The recognition of Travellers as an ethnic group informs all the work of Pavee Point. Our analysis has been recognised in various forms and by various national and international organisations over the years. However, the national government here is currently displaying a resistance to this analysis that could have far reaching implications for Travellers.

In its first report to the UN Convention on the Elimination of All Forms of Racial Discrimination (CERD), the Irish Government has failed to recognise Travellers as an ethnic group. Our work must now focus on highlighting this failure both here at home and abroad. Pavee Point will be producing a shadow report to the Government's report, regarding Travellers, and will be highlighting to the Government how the UN defines Travellers, Roma and Gypsies as minority ethnic groups.

Meanwhile Pavee Point, as an organisation, is continuing to review its approaches in its work in addressing Traveller issues, particularly in the light of Government cutbacks. We hope to bring you further information on this in future issues.

Ronnie Fay,  
Director.

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# The Health Strategy Now

The National Traveller Health Strategy 2002 - 2005 was launched in February 2002. It represents a change in national policy towards Travellers as, firstly, it recognises Travellers as a distinct minority ethnic group with a health status far below the majority population.

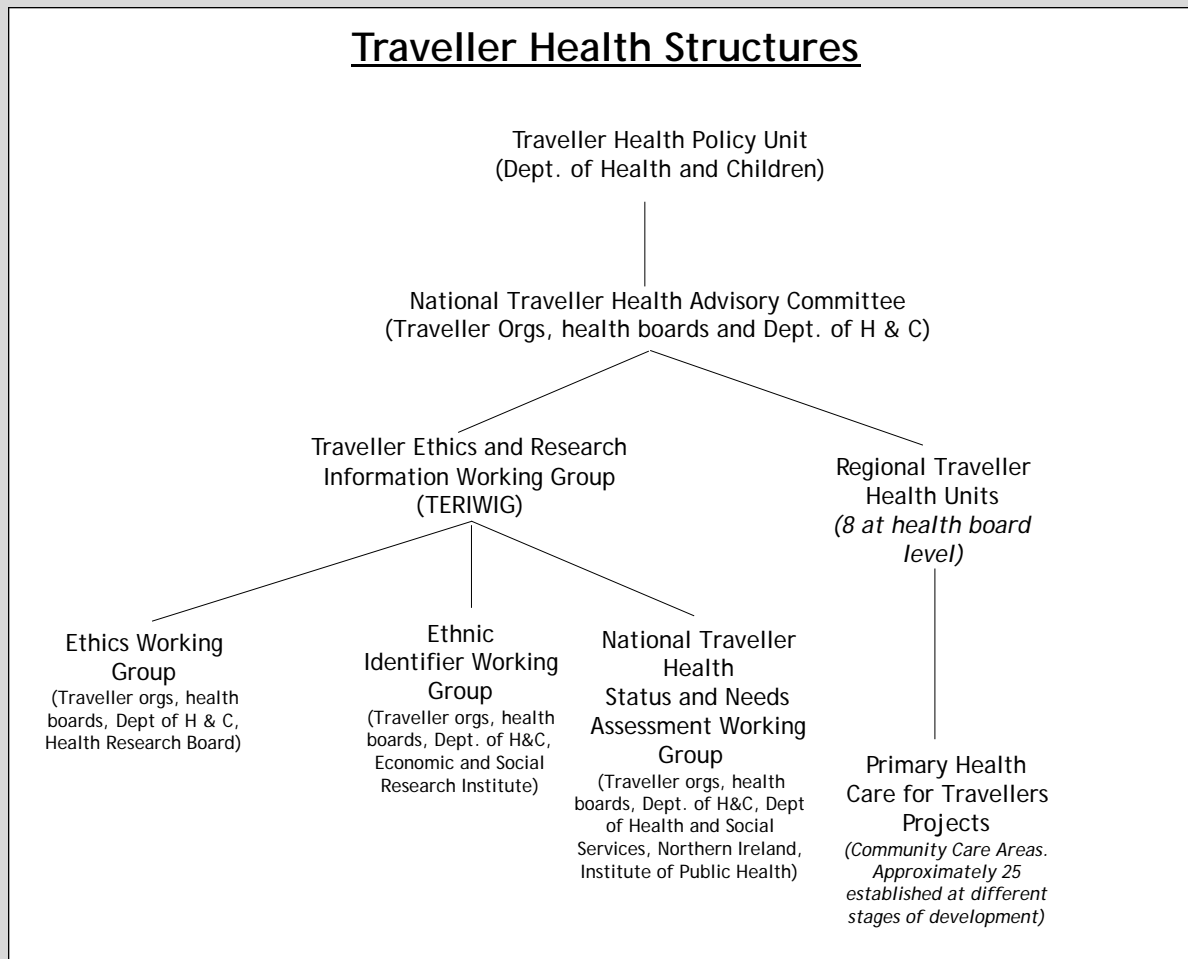
It also recognises that social exclusion, racism and living conditions have an impact on health status. On this basis this Strategy was welcomed by Travellers and Traveller organisations nationally, who participated and contributed to the Strategy. €8.4 million was allocated for the implementation of this strategy over a four year period.

A year and a half down the road significant elements of the Strategy have been carried out:

- There are new and revamped structures in place to implement the Strategy.
- Consultations with Travellers has begun in drawing up a design for a Traveller Needs Assessment and Health Status Study
- Traveller Health Units around the country have drawn up Regional Action Plans in terms of Traveller health.
- Primary Health Care Projects have been in development around the country.

The National Traveller Health Advisory Committee was the driving force behind the drawing up of the National Traveller Health Strategy. Similarly, it is the driving force behind the implementation of the Strategy at both national and regional levels. It is made up of representatives of the Department of Health, Traveller organisations and Health Boards.

At national level the Traveller Ethics and Research Information Working Group (TERIWIG) is co-ordinating three major aspects of the Strategy. In the following pages we outline the work of the TERIWIG Committees. We also ask how real is the progress in Traveller Health.



# Ethics & Research Working Group

## *Guidelines on Ethical Research*

By Rosaleen McDonagh, Pavee Point

There is a long history of research on Travellers. In fact, Travellers are probably the most researched group in Irish society. But this research has brought few benefits to the Traveller community and has often resulted in the exploitation of Travellers.

The National Traveller Strategy highlighted an overflow of research on Irish Travellers but noted that research is not consistently reviewed against sound ethical principles and good research practice.

Travellers have been used as tools and objects in research that fails to look at how it can benefit the Traveller community or how researchers can engage with Travellers on an equal basis.

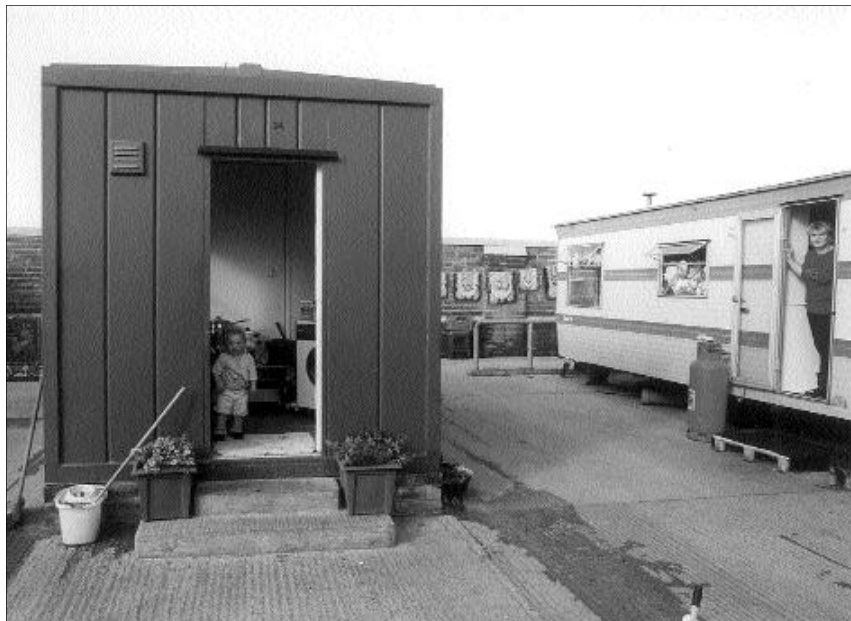
One of the key roles of TERIWG is to carry out an initial and continuing ethical review of all research projects involving Travellers to assure that:

- the rights and welfare of Travellers involved in the research are adequately protected
- the rights pertaining to the confidentiality and privacy of Travellers are protected
- the risks to Travellers are reasonable in relation to the potential benefits, if any, to the subjects, and the importance of the knowledge to be gained, and
- informed consent is obtained by methods that are adequate and appropriate.

TERIWG have authority to approve, or disapprove all research activities presented to it for review.

Currently this committee's drawing up guidelines on ethical and culturally appropriate ways of carrying out research. Often research, carried out by members of the majority population, puts little value on important aspects of Traveller life - storytelling and personal narratives, for example.

Travellers must be given ownership of research on their community and have an input into the analysis and priority given to particular issues.



*Travellers must be given ownership of research on their community and have an input into the analysis and priority given to particular issues*

### Remit of Working Group

- The setting and maintenance of appropriate standards in health research for Travellers
- Development of an appropriate code of practice regarding research and training with Travellers
- Making recommendations regarding the approval, co-ordination and monitoring of official research relating to Travellers' health
- Co-ordinating and monitoring the research into Travellers' health proposed in the National Traveller Health Strategy.

In some cases the Committee may ask researchers to come back with modifications or reassurances.

In drawing up ethical guidelines there is an emphasis on research being culturally appropriate. This will hopefully ensure added value for Travellers, ensure full Traveller consent and full Traveller participation.

For further information contact Martin Kestell, Department of Health and Children, Dublin 2. Tel: (01) 635 4073.

# Ethnic Identifier Working Group

## Ethnicity Pilot Project

By Hugh Magee, Chief Statistician, Department of Health and Children.

The need for data on ethnicity is widely recognised as is the requirement to update, develop and mainstream indicators of the health status of Travellers and other ethnic minorities.

### Pilot Project to Collect Data on Ethnic Group

The purpose of the Ethnicity Pilot Project is to develop, test, and evaluate the collection of information on the ethnicity (including Travellers and other ethnic groups) of hospital patients. It covers Actions 8 and 9 of *Traveller Health: A National Strategy (2002-2005)* which have the central aim of progressing towards the measurement of ethnicity as a routine feature of health information systems. As the Strategy states:

*This data, effectively the baseline from which progress can be measured and by which services can be planned and monitored, is now an urgent necessity. However, for the purpose of effectively gathering information on the health status of the Traveller community, it may be necessary to modify health information systems in order to identify Travellers as an ethnic group. (Strategy, p.35).*

The pilot project will complement the Traveller Needs Assessment and Health Status Study (Action 10) which is now being designed. It is hoped that a successful pilot will serve as a guide for the standard measurement of ethnicity across health and other administrative information systems.

### Aims of Pilot Project

The project is designed to collect information on ethnicity in a major acute hospital and a major maternity hospital for a limited period and to undertake analysis and evaluation of

the results. The two hospitals which have agreed to participate are the Adelaide and Meath Hospital incorporating the National Childrens' Hospital (Tallaght) and the Rotunda Hospital.

In both hospitals, careful preparation and training for the introduction of the ethnicity question will be essential as will more general awareness raising within the community about the project and its potential value. Pavee Point will take a lead role in implementing these critical aspects of the study and in their evaluation.

### Giving Data is Voluntary and Confidential

It is important to emphasise that participation in the pilot project will be completely voluntary, that respondents will self-identify and will be made fully aware of the aims of the project and of the use which is to be made of the data. In particular, the data will be used solely for statistical purposes and under no circumstances will it be used to identify individuals.

Analysis of the pilot project's results will involve a number of perspectives - the preparation and training, the question and the data collected

### Progress to Date

The project can best be seen as having three fairly distinct phases. The first is to agree an ethnicity question and to prepare and implement training programmes; the second is to do the data collection; and the third is to look at, analyse and report on the results.

As of now, the project is about half way through the first phase. This may seem like slow progress since the project was begun a number of months ago. However, preparing the groundwork in terms of question

design, awareness raising in the community, and training materials/programmes are complex, time-consuming exercises critical to the success of the work.

An expert group gave their time and assistance to the task of developing an appropriate ethnicity question. This included representatives from the participating hospitals, from the HIPE/NPRS Unit at the Economic and Social Research Institute, from the Department of Health and Children and from a range of national organisations working with ethnic minorities including Pavee Point, the Equality Authority, the Institute of Public Health, the Irish Refugee Council, the National Consultative Council on Racism and Interculturalism (NCCRI), Cairde, Sporasí and Access Ireland. Recognising the complexity and sensitivity of the issue, a balance had to be reached between the need for simplicity/efficiency on the one hand and sufficient detail to allow meaningful results on the other. An important outcome for the project will be the evaluation of our success in arriving at the right balance and suggestions for improvement as required.

### Next Steps

The project expects to begin awareness raising and training for the implementation of the project in the near future. Training materials and programmes are in the process of being developed and agreed with the participating hospitals. This will be followed as quickly as possible by phase two: the collection of data. Depending on decisions yet to be finalised on how long data collection will continue, it is expected that the final results of the project will become available around the middle of next year.

# National Traveller Health Status and Needs Assessment Working Group

## The Travellers' All-Ireland Health Study

By Kevin P. Balanda, Institute of Public Health in Ireland

### Why a Traveller All-Ireland Health Study?

The Travellers Health Status Study 1987 commissioned by the Health Research Board in the Republic, gave rise to considerable concern about the health status of the Traveller community. It was an epidemiological<sup>1</sup> study that found, amongst other things, that

- Travellers have infant mortality rates 3 times higher than the national rate.
- Traveller men live on average 10 years less than settled men.
- Traveller women live on average 12 years less than settled women.
- Travellers of all ages have very high mortality rates compared to the Irish population (1,2,3).

The other most widely quoted regional research was conducted by Ginney in Belfast in 1991-1992. It took a very different approach and used methods that were ethnographic and based on "elicit(ing) the naturally occurring health knowledge which is used to informally by Travellers themselves." (4). Ginney's research put Travellers health in the context of the historical/contemporary racism and discrimination they experienced. It recognised the need to enhance Traveller cultural values and cultural norms rather than impose a value system whereby natural remedies and cures were ignored and Traveller culture was denigrated.

Since these studies there has been a range of locally based research on the island. However, none allow for population level analysis, many are small-scale studies that focus on local issues related to service provision, and sampling and representativeness issues often limit their use at a regional or broader level. At present there is no up-to-date study of the health of Travellers in either Republic or Northern Ireland.

### What is the Travellers' All-Ireland Health Study?

The Travellers' All-Ireland Health Study will be the first study of Travellers' health status and health needs that involves all Travellers living on the island, North and South. The study will assess health needs, as identified by Travellers and service providers, and measure the health status of Travellers. The

two parts of the study will run in parallel and will support and complement each other so that the outcome will be a holistic understanding of the health situation of Travellers.

### How did the Travellers' All-Ireland Health Study come about?

The Traveller Health - A National Strategy 2002-2005 in the Republic includes a commitment to "carry out a Traveller Needs Assessment and Health Status Study to update and extend the indicators used in the last survey of Travellers' Health Status and to inform appropriate actions required in the area of Travellers' health" (5). The National Strategy also led to the formation of the Traveller Ethics, Research and Information Working Group whose remit included the co-ordination and monitoring of the study during the Strategy's term (2002-2005). The Working Group strongly supported the idea of an all-island study.

In the meantime the government in Northern Ireland produced number of recommendations aimed at improving the health and well-being of Travellers (6). The Department of Health, Social Services and Public Safety were keen to participate in an all-Ireland study of Traveller health and saw it as a useful tool for developing future policy.

Consequently the Travellers' All-Ireland Health Study Group was established to oversee the development of the study that was renamed the 'Travellers' All-Ireland Health Study'. The Study Group currently includes representatives from Department of Health, Social Services and Public Safety, the Department for Health and Children, the Health Boards, the Health Research Board, Pavee Point and Traveller Movement (NI). Pavee Point is the lead agency for Travellers / Traveller organisations in the RoI and Traveller Movement (NI) represents Traveller organisations in Northern Ireland.

### Designing the study

To design a study such as this one, a number of key issues have to be discussed:

- What should the study aims be?
- What methods should be used to achieve them?
- Who should be involved in the conduct of the study?

- How should results be analysed?
- How should the study be managed?
- How do we ensure that results are translated into policy and practice?

To be successful, this study must address priority issues, use methodologies that are culturally appropriate, gather only necessary information, and yield results that are relevant and acceptable to the Traveller community and that can be translated into meaningful policy and practice.

In order to achieve this, the Study Group believed that Travellers, Traveller organisations and health services had to be involved from the very beginning, and it decided that a separate process to design the study was necessary. The funds to design the study were jointly provided by the Department of Health and Children in the Republic and the Department of Health, Social Services and Public

1. A review of existing research on Travellers' health
2. A written consultation to identify the broad dimensions of the study
3. Production of a discussion paper
4. Regional consultations to consider the paper and address local and regional issues
5. Production of a draft study design
6. An all-Ireland feedback event to complete the study design
7. Submission to governments for funding

#### Progress to date

During the earlier part of this year steps 1 and 2 were completed.

4. A discussion paper which sets out some of the key issues that need to be discussed was prepared and recently distributed.



*This will be the first study of Travellers Health Status and health needs that involves all Travellers living on the island, North and South.*

Safety in Northern Ireland. When decisions have been taken in relation to the key issues listed above, a submission will be made to both governments for approval to conduct the study as recommended.

The Institute of Public Health in Ireland, an all-Ireland body with a focus on tackling health inequalities across the island, was asked by the Study Group to undertake the design work in collaboration with Travellers and Travellers organisations and health services.

To design the study the Study Group asked the Institute to follow a series of seven steps:

5. This discussion paper is intended as a resource for the nine regional consultations (eight in the Republic and one in Northern Ireland) that are being run in September 2003 to address local and regional issues.

#### Next steps

Steps 5, 6 and 7 will take place between now and January 2004. It is hoped the Study itself will take place in the latter part of next year.

# Cousins Marriage Not Harmful - Say the Experts

**The Traveller Consanguinity Working Group recently produced a position paper on cousin marriage. This group is made up of medical experts, representatives of the Roman Catholic Church and Traveller organisations who were asked to report to the Department of Health as part of the National Traveller Health Strategy. Here we explain the report.**

Consanguineous marriage is a marriage between two people who are biologically related as second cousins or closer. Since the mid-19th century, the accepted wisdom in Western medicine has been that first cousin marriages should be discouraged because they have an increased risk of producing children affected by inherited disorder.

However, advances in genetic studies now enable us to benefit from better insights and improved approaches.

Cousin marriage is practised among Irish Travellers. Various studies have estimated that between 19% and 40% of Traveller marriages are between first cousins.

It has been claimed that a large proportion of childhood illness and mortality within the Traveller community is due to inherited disorders.

It has also been claimed that inherited disorders are more common among Travellers because of the custom of cousin marriage. Neither of these two claims are supported by recent studies of genetic disorders in Ireland.

In reality only a small number of inherited disorders are more common among Travellers than among the general population. Worldwide there are many examples of altered genes that are more common in certain populations than in others. An example of this is Phenylketonuria (PKU) which is more common in Ireland than in the rest of Europe.

In such cases, it is the history of the population and the forces that have shaped it over thousands of years that have determined the frequency of these disorders and their underlying genetic alternations in present day populations.

The risks in terms of cousin marriage only occurs if there is already a history of genetic disorder within the family. Where both parents carry the same altered gene, each of their children has a one in four chance of inheriting both altered genes and so have the disorder. Because they are related, parents who are first-cousins are more likely to have inherited the same altered gene from a common ancestor. This fact increases their risk of producing an affected child.

A number of major studies have shown that, for first-cousin marriages, the risk of death due to these type of disorders is between four to five per cent higher than in the general population.

As in other populations where consanguinity is a cultural norm, it is likely (based on clinical studies) that the increased risk of inherited disorders within the Traveller community is limited to a number of families.

## Community Genetics

Members of the Travelling community who are planning a consanguineous marriage can be helped to assess their risk of having children with an inherited disorder through a community genetics approach to consanguinity.

Community genetics involves the provision of genetic services dedicated to a particular ethnic group or community, taking into account those disorders that are common in the community. The services are provided on a voluntary, confidential basis and in a manner that respects the cultural norms and sensitivities of the community.

This begins with genetic counselling where a couple has a confidential consultation and a detailed medical history over 3-4 generations is drawn up. If there is no history

# Two Views

By Kathleen Joyce, Community Health Worker, Pavee Point



Until about six years ago I knew nothing about consanguinity I never even heard the word or that it had anything to do with first cousins intermarrying. I am a Traveller and come from the Traveller community so I know we were intermarrying for years and it was going on for generations.

Travellers around the country see nothing wrong with this custom and I personally feel the same way. So I was glad this paper compiled by the Working Group is for Travellers and is about consanguinity, because it is challenging peoples view points in relation to intermarriage among Travellers.

Benefits of having cousin marriages have always been clear to Travellers. For one thing you know where your daughter or son is going and you know who you are getting. But it is also clear to Travellers that marrying your cousin doesn't mean you are going to have a sick child. Even though there are children born to Travellers that have disorders it is very rare and does not effect the vast majority of Travellers.

I always knew that we could not be the only ethnic group in the world that practiced intermarriage, but I was very surprised to hear from Professor Alan Bittles when he was doing a lecture in Dublin, that over 900 million people worldwide marry their cousins or closer and that this was very acceptable in other countries.

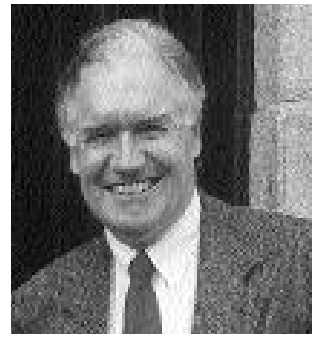
Getting married is a major event for a lot of Traveller families. It is a time of celebrations and uniting or strengthening family ties. So, it is very important that nothing happens that will put young people's marriage prospects in danger.

People through the years have had a lot of misinformation regarding consanguinity, and the possible effects of first cousins marrying. A lot of the information people get about consanguinity is not factual. A lot of the claims made about cousin marriage have never been proven because comprehensive studies have never been carried out. So, unless people have accurate information, they cannot make informed choices

This was why I was glad to hear that in the National Traveller Health Strategy it says that there should be a study to find out the causes of genetic disorders among Travellers. Once people are aware of these disorders then you could do your best to keep them to a minimum.

I have only one child and she will be able to make up her own mind on who she wants to marry when she is older. If she wants to marry a cousin, I hope that people's attitudes will have changed and services that she may or may not need are in place.

By Professor Alan Bittles, Edith Cowan University, Perth, Australia.



Although it is difficult to gauge what the present level of first cousin marriage is within the Traveller community, and different groups probably vary in the degree to which they choose to marry a biological relative, there seems little doubt that close kin unions represent a longstanding and valued tradition.

The Roman Catholic Church requires that first cousins who wish to marry must obtain prior Diocesan approval, and as devout members of the Church this regulation is respected by the Traveller community.

While in most cases the Church had been prepared to grant such dispensation, a change occurred during the early 1990s which resulted in Travellers being refused dispensation

Some specific inherited disorders are more common among Travellers than in the general Irish population. But as detailed on the website [www.consang.net](http://www.consang.net), of itself first cousin marriage does not cause ill-effect. Rather, by chance alone, harmful genetic defects can multiply within enclosed communities from generation to generation. Therefore, refusal of dispensation for first cousins to marry would be singularly ineffective in preventing the conception of children with an inherited disorder.

In addition, denying the right to marry a chosen spouse devalues and negates the social benefits that many Travellers believe are offered by cousin unions. This latter point was made by the late Dr. Michael Flynn, a well-known and much loved medical practitioner in Mullingar who died earlier this year. In his autobiography published in 2002, Dr. Flynn wrote 'If it is part of Traveller culture, let it be and the community at large must recognise that consanguineous marriage has benefits, which must be set against the occasional occurrence of gene variation'.

As its next step the Working Group will be gathering information on the prevalence of genetic disorders within different Traveller communities, and in conjunction with Traveller representatives and the Church has produced guidelines as to how the problems posed by genetic disorders can be minimized. Besides the reassurance offered to Traveller families, it can be anticipated that the guidelines will be of great value to the many indigenous and migrant communities around the world in which consanguineous marriage is traditionally preferred.

# How Real *is* The Progress *in* Traveller Health?

By Bridget Quirke, Pavee Point.

**G**reat strides have been made with the introduction of the National Traveller Health Strategy. It is key that a range of sub-groups have been established to support the implementation of some of the key recommendations in the NTHS.

## Regional Structures Key to Success

Over €8 million was allocated for the implementation of the NTHS. This funding is allocated to the health boards locally and is then processed by the Traveller Health Unit (see graph page 3) structures at regional level. So the effectiveness of the THU is critical to the success of the NTHS.

Funding has been allocated to Travellers health since 1998 and in that period a lot of positive developments have taken place with these additional resources, notably the increase in the number of Primary Health Care for Traveller Projects. These have increased from 4 to 20 in the last 5 years. A number of designated positions have also been established within the public health nursing and social work service.

The launch of the NTHS indicated a positive commitment by the Department of Health and Children to Traveller Health, but that commitment is not being translated into the necessary allocation of budgets at health board level.

Recently health boards have been holding back on the allocation of THU budgets, due to the pressure of having to balance their books. One CEO said, "my job is to balance the books, all monies that come to my board belong to me, and I decide how they are to be spent and what are the priorities, there is no such thing as ring fenced monies."

## Lack of Accountability at Local Level

As part of the role of the National Traveller Health Advisory Committee, we carried out a national review of the Traveller Health Units in 2002. It was an interesting process, all the six units established (2 health boards had not established THUs) were working at varying degrees of effectiveness and we

identified some very good models of best practice.

Some THUs were seen to be working in a true spirit of partnership and listening to Traveller concerns. Others had invested a proportion of their budget to help improve the capacity of their Traveller representatives.

Initiatives which displayed an innovative and creative approach to Traveller health were identified. And, the THU were often shown to be achieving better priority for Traveller health within the health board system.

However, the most worrying outcome of the review was lack of accountability for the resources allocated to the health boards. At the time of the review approximately €4 million was allocated to be spent by the Health Boards via their THUs since 1998 and less than 50% of these resources were accounted for by the local THUs.

It would appear that in the absence of the NTHS, some health boards kept back the money or used it for other services. This was quite shocking, as we understood the money was 'ring fenced' and could only be used for Traveller health. As the Traveller representative on the NTHAC, Pavee Point is still trying to get accurate accounts from the health boards.

We have also asked the local Traveller representatives on regional units to follow this up, and they confirm that they are not advised of all the monies allocated. In some cases only a percentage of the money allocated is made available for the work on the THUs. This is of great concern, as we are aware that the €8 million allocated is already inadequate to implement the NTHS. If existing resources are not all being used for Traveller health, we will never achieve the improvements necessary in Traveller health.

## Health Cut Backs

This year the NTHS was originally allocated 1.9 million euros at national level, but only 1 million was allocated to the health boards due to cut backs

nationally. At regional level, some boards are holding back on the allocation to the THUs and will decide to distribute if monies are left in their budget. Some THUs have just received their allocation and must spend it, in the last quarter of this year.

Another worrying development at regional level, is that services accessed by Travellers which previously part of the mainstream, are now being paid for out of the THU budget. This is not how it is understood the budget was to be spent. NTHS funding was meant to implement the Strategy not to pay for existing services. Travellers are part of the community and should therefore be included in all other services. Do the THUs now have to pay other health care services to provide for Travellers.?

## Other Cut Backs

The situation for Traveller health has also been seriously affected by cutbacks from other areas, notably, cutbacks within FÁS, Community Employment, the Community Development Support Programme and childcare schemes. These monies support the Traveller organisation infrastructure, without which it is very difficult to support the development of a Primary Health Care Project or health initiative. Cutbacks or lack of commitment to funding from FÁS, has had a devastating effect on the current training programmes for Primary Health Care. This ranges from health boards not funding projects, to discontinuation of projects, to loss of places on projects due to insufficient resources. This has led to some THUs having to make choices on funding to support Primary Health Care projects, to the detriment of other projects or new initiatives.

## Seeking Meeting with Minister

These issues have been raised by us at the NTHAC, and an urgent report is being prepared by the NTHAC for the Minister of Health and Children, Micheal Martin, TD. This situation was discussed with members at the last meeting of the National Traveller Health network. It was agreed that a letter would be prepared to seek a meeting with the Minister to discuss these serious developments and concerns that Traveller organisations have regarding current cutbacks in Traveller health.

# Problems *with* Postal Delivery to Traveller Accommodation

In 2001 a roundtable discussion on 'Trade Unions and Travellers' focused on equality in service provision. Traveller women involved in Pavee Point's Cultural & Heritage Group documented their experience of postal delivery services in the Finglas area of Dublin. They highlighted a number of problems with postal services and noted how poor services negatively impacted on their lives. In 2002 Pavee Point Mediation Service invited the Communication Workers Union and Travellers to meet to discuss postal delivery issues and questionnaires were distributed to Traveller focus groups for consideration in Limerick, Galway, Wicklow (two groups) and one Dublin suburb.

## Research Findings

The research findings mirrored the experience of the women in Finglas with all areas reporting difficulties in accessing their mail. The most serious problems were reported by Travellers living in Traveller specific accommodation: Group Housing Schemes; Halting Sites (official/unofficial) and road side encampments and included the following:

- Individuals being handed post that was not addressed to them.
- Post being handed to one individual on a site/scheme (often a child) with the expectation they deliver post to others on site/scheme.
- Post not always delivered each day but accumulated and delivered once a week.
- No delivery on some sites and no arrangements in place for collection from local sorting office or post office in some areas.
- Delivery of post to local Traveller Support Group for distribution to residents.

## The Personal Impact

The impact of poor (or no) postal services on the daily lives of Travellers includes:

- Missed medical appointments due to non or late delivery of post.
- Non-delivery or delivery to the wrong address of important documents.
- Breakdown of communication and general lack of information for postal service customers.
- Breakdown in community relations and growth in suspicion of neighbours if post has gone missing or is believed to have been delivered to the wrong address.

## Why Are Postal Services to Travellers so Poor?

Respondents felt the reasons why services to Traveller sites are so poor may include:

- Fear of dogs on sites.
- Prejudice and discrimination against Travellers by some postal delivery staff.
- Mistaken belief that Travellers sharing the same surname belong to the same family and should sort out their own post.
- Carelessness on behalf of some postal delivery staff. (It must be noted that many respondents stated that some delivery staff were very good while others were careless about their work).



*The most serious problems were reported by Travellers living in Traveller specific accommodation.*

## Discussions with Members of the Communication Workers Union (CWU)

CWU representatives informed Travellers that responsibility for delivery of post to all customers lies with An Post. CWU members delivering post work to guidelines developed in the early 1960s. These guidelines set out the rules for delivering post to houses and to companies, but not to halting sites. The CWU highlighted the need to engage with An Post with a view to developing protocols in relation to delivery of post to halting sites. Postal delivery services to Travellers living in group housing schemes or standard housing should be governed by existing protocol and Travellers should expect the same standard of service as other communities.

It was observed that failure to meet the needs of Traveller customers who do not live in standard housing is a form of institutional racism in that the postal service has been developed solely with the needs of the majority settled population in mind.

The current protocol (Rule Book) determines that:

- Post should only be delivered to houses with letterboxes.
- Delivery is to the house number and address on postal items, regardless of name.
- If the name or address on a letter is unclear, protocol allows postal delivery staff to make enquiries of local people to try to identify the addressee.
- Post not delivered will be held in a sorting office for three days unless a retention order, asking An Post to hold post in the sorting office for collection, is in place. People should bring identification to the sorting office when collecting post.
- Customers can ask for post to be held (retained) in the sorting office for collection for a fee. A "Mail Retention Form" can be obtained in any Post Office.

CWU representatives agreed with Travellers that dogs on sites can cause a problem for delivery services and asked that customers be aware of this. The group agreed that where people have dogs it is important to control them.

Complaints to An Post in relation to postal delivery services should be made to the Customer Relations Section and not to local post offices.

## What Happens Next?

The Communication Workers Union have given a commitment to work closely with Pavee Point Mediation Service, members of the Traveller community, An Post and local authorities to explore solutions to the difficulties faced by Traveller customers.

## JOHNNY DELANEY

It was with great sadness and outrage that Pavee Point heard about the brutal murder of 15-year-old Irish Traveller Johnny Delaney in Liverpool on 2nd of June. Johnny was beaten to death in the middle of a playing field in Ellesmere Port.

The Delaney family believe the attack on Johnny was unprovoked and that he was killed because of his Traveller identity. When Johnny was found - a Ribena bottle and a packet of crisps were found by his side. Two boys, aged 15 and 16, have been charged with his murder. But, police say they cannot comment on whether they are investigating if the attack was racially motivated.

An Aunt of Johnny's told newspapers: "We can't think why anybody would attack him, except because he was a Traveller. No matter how much we have, we are still dirty Gypsy bastards. No matter how good you can be to people, they still treat us the same way."

Johnny's brother Michael told how once he was at a fairground with his brother when a gang of boys came at them - one with a knife calling them 'you Gypsy this and you Gypsy that'.

Johnny's body was recently returned to Ireland for burial. A tribute to Johnny was written by his mother and Aunt Bridget Doran:

### Johnny

My best friend who I loved so.

I was there and watched you grow.

Warm was our heart with so much pride  
When you were there by our side.

The joy and laughter through the years.

We didn't think it would end in tears.

Johnny you're constantly in our thoughts

The way you life ended has left us all distraught.

But, I know there's a garden in heaven above

And it's filled with flowers and eternal love.

All the angels gather for a while just to see your  
beautiful smile.

In God's care you rest above in all our hearts you rest  
with love.

Dear Johnny you were so brave the day your life was  
taken away.

But we know that his is not the end. Goodnight, God  
Bless until we meet again.

## Equal Project *Gathers Steam*

The Pavee Point EQUAL Project is up and running with all 3 pilots fully subscribed. The aim of the project is to support the Traveller Economy by supporting Traveller men who want to develop, or formalise new businesses.

The pilots are being run in Galway, facilitated by Charlie Currie; Clondalkin facilitated by Helen Miller and Pavee Point, facilitated by Patrick Nevin. There are 29 participants in all with a waiting list of more than half that again.

The Pavee Point Equal Project has been involved in SAFEPASS training, group meetings and individual sessions to identify potential self-employment opportunities. All 14 participants were successful in the SAFEPASS test and gained their passes which are essential in order to obtain employment on building sites. Teleporter and driving lessons, assistance to gain a D licence and driving theory tests have been identified as useful skills. In Galway participants have undertaken a computer course.

A 12 session course in Horticulture/ Garden maintenance is underway in Pavee Point which will include Cobblelock and path laying.

As well as enterprise-related subjects the men have also been engaged in discussion on Traveller issues, attending ITM legal unit consultation workshops in Galway and Dublin, and the launch of the legal unit at the ITM AGM.

Dr Philip Crowley facilitated a session on men's health in Pavee Point which was greatly appreciated and provoked a lively discussion about the access of men to health services, particularly GPs.

As part of the project plan is to produce a video to document the activities of and disseminate the learning from the project. JDM productions from Galway have been commissioned to work with the pilots. Filming has started and will take place over the duration of the project with the final video to be ready for distribution in 2005.

For any further information about the project please contact: Elizabeth Davidson, Project Coordinator, [te@pavee.iol.ie](mailto:te@pavee.iol.ie)



## TRAVELLER CHILDREN - Lets Hear Their Voices

Pavee Point seeks to contribute to 'the generation of conditions for young Travellers and children to exercise full citizenship internally within the Traveller community and in the wider society' (Pavee Point strategic plan 2001-2005) Against this backdrop the organisation is about to initiate a national project, entitled 'The Voice of Children'. This project will:

- a) test a process for enabling and empowering young Travellers to articulate their experiences and opinions
- b) develop a resource that outlines this process, articulates some of the issues raised by participants and advises on deeper issues relating to consultation with young people from minority groups. Pavee Point is seeking partners for this project.



*Pavee Point is seeking to collaborate with organisations working at a local level with young Travellers in the operation of this project.*

It is funded by the National Children's Office and is linked to the National Children's Strategy goal: '*Children will have a voice in matters which affect them and their views will be given due weight in accordance with their age and maturity*'.

The project has arisen from recognition that recent efforts at a national level, through Dáil na nÓg and more recently Comhairle na nÓg operated through the County Development Boards, to consult with children and young people fail to reflect fully the voices, opinions and concerns of young Travellers. There is a need to understand the reasons behind this and to develop and test a process that is designed to enable young Travellers to articulate their experiences and opinions and have their voices heard.

It is planned that this process would culminate in the young people making a visual/physical presentation of one of their issues during an end-of-project event. This work will feed directly into the work of the National Children's Office on the Voice of the Child. It is proposed to test this process of consultation with up to six groups of young Travellers around Ireland. The exact nature of these groups has not yet been decided, but it is envisaged that there would be at least one pre-school group and a number of youth groups of different ages. A mixed Traveller/settled group may also be included in the process.

Pavee Point is seeking to collaborate with organisations working at a local level with young Travellers in the operation of this project. An exact timescale for the project has yet to be agreed, but it is envisaged that it will run from October until May 2004. If your organisation is interested in participating in this process or if you would like more information on the proposed project, please contact Colette Murray: 01 8780255 email: colmurray@connect.ie

### PAVEE POINT SUMMER PROJECTS

The big success of this year's Summer Projects was a disco that took place at the end of the projects. About 60 young people attended the disco in Cara Park Hall, Coolock. There was soft drinks and food and spot prizes as well as dancing.

"It was bad at the start. I thought nobody would of gotten up dancing, but then it started to get good during the middle. Everyone got up dancing. I really enjoyed myself. It was very good. We should have another disco," said John Collins.

Traveller young people from Belcamp, Finglas and Coolock took part in the Projects which also included a day at an adventure centre, a walk and games in the Wicklow Mountains, a trip to the beach and a visit at Dublin Zoo. The Summer Projects could not have taken place without the support of funders: Bank of Ireland Arts Centre, Crossan Cars Ltd., Diageo Ireland, Smurfit, Gallaher (Dublin) Limited, Coca Cola, Electric Aid, CDYSB and Dublin Corporation.



*R to L April Ward, Mary Collins and Joleen Gallagher from Belcamp taking part in Adventure Sports*



*Anne Marie O'Donnell, Davy O'Reilly and Sheila McDonnell from Dunsink, Finglas at Dublin Zoo.*

# Government *fails to recognise Travellers as a minority* Ethnic Group

Up to now the Irish state has been reluctant to formally recognise Travellers as a minority ethnic group within Irish society. Yet there has been implicit recognition through, for example, the involvement of Traveller representatives on the co-ordinating committee for the European Year Against Racism (1997) and the National Consultative Committee on Racism and Interculturalism; and Ireland's reports on a variety of international agreements.

However this year in preparation for its first report on CERD (the *United Nations Convention for the Elimination of All Forms of Racial Discrimination*), the State has argued that the definition of racial discrimination contained in this Convention does not include Travellers.

In CERD the term 'racial discrimination' is defined as meaning "any distinction, exclusion, restriction or preference based on race, colour, descent, or national or ethnic origin which has the purpose or effect of nullifying or impairing the recognition, enjoyment or exercise, on an equal footing, of human rights and fundamental freedoms in the political, economic, social, cultural or any other field of public life." (Article 1.1 CERD)



**Travellers - a minority ethnic group**

Paragraph 3 of the executive summary of the Government's report states that "In this regard to the scope of the report it should be noted that Irish Travellers do not constitute a distinct group from the population as a whole in terms of race, colour, descent, or national or ethnic origin. However, the Government is aware that members of the Traveller Community suffer discrimination on the basis of their social origin. The Government is committed to challenging discrimination against Travellers and has defined membership of the Traveller Community as a separate ground on which it is unlawful to discriminate under equality legislation. The Government notes that the Durban Declaration and Action Plan recognised the need to develop effective policies and implementation mechanisms for the full achievement of equality for Roma/Gypsies/Travellers and has included at Appendix 1 a report on legislative, administrative and other initiatives taken to combat discrimination against members of the Traveller community." (p4)

This position strikes Pavee Point and many others seeking to address racism and discrimination in Ireland as a very odd and contradictory one. General Recommendation No XXVII issued by the CERD committee refers to 'Discrimination Against Roma' and makes clear that CERD is applicable to

Roma. Both within the Durban Declaration and within work undertaken by the Council of Europe there is a growing acceptance that when discussing Roma issues one is also discussing issues of relevance to Travellers and Gypsies. It is particularly odd as paragraph 136 of the draft report refers to Ireland's report under the Council of Europe's Framework Convention for the Protection of National Minorities and notes: "As part of our obligations under this Convention, Ireland commissioned a report on national minorities in Ireland, we have one currently recognised group: Travellers." National origin is included in the CERD definition of 'racial discrimination'.

## Recognising ethnicity...

In a recent judgement on Irish Travellers ethnic status in Britain it noted "that of the two essential characteristics, namely the long shared history and the cultural tradition, we are satisfied that both of these criteria have been sufficiently satisfied.... It follows, therefore, that our conclusions clearly are that we are satisfied that the Mandla criteria are satisfied in this case, and therefore Irish travellers may be properly identified as an ethnic minority, so we answer the preliminary question in the affirmative." (p39)

The Equal Status Act's definition of Travellers is based on the definition used in the Northern Ireland Race Relations Order, which evolved out of British case law. This definition says that " 'Traveller community' means the community of people who are commonly called Travellers and who are identified (both by themselves and others) as people with a shared history, culture and traditions including, historically, a nomadic way of life on the island of Ireland." Travellers are identified both by themselves and others as a separate group within Irish society. The state acknowledges this in the appendix on Travellers when it noted that "Irish Travellers (population 24,000) are an indigenous Irish community with a shared history of a nomadic way of life and cultural identity." (p87) In effect two of the key elements of ethnic identity identified in British and other jurisdictions!

Pavee Point has secured funding from the Joseph Rowntree Trust to do a shadow report for the CERD Committee on the position of Travellers within Irish society; and the implications for Travellers socio-economic inclusion of the State's on-going refusal to acknowledge the nature of this exclusion as racism. A series of regional workshops will be held to inform this report.

# CENSUS 2002 - *THE RESULTS*

Census figures on the Traveller community were published on the 19th of June. These figures were facilitated by a Census question asking - Are you a member of the Traveller Community?

The fact that only Travellers were asked to identify themselves in terms of their ethnicity is the main weakness we see in this Census. It undermines the confidence that we can have in the completeness of these figures. We believe that there may still be a substantial undercount of the full numbers of Travellers.

We estimate this undercount to be as much as 20%. Each year local authorities do a count of Traveller families. According to these figures for 2001 there are 30,900 Travellers. According to Census 2002 there are 23,681 Travellers.

Two key principles in ethnic data collection are self-identification and universality - ie the person being counted determines what ethnic group he or she belongs to. And that everybody is asked to identify their ethnicity. Census 2002 only achieved in one of these areas - self-identification and counted almost 24,000 Travellers. We estimate there may be 30,000 Travellers in the country. The implications of an undercount are obvious if we think of planning Traveller accommodation, for example.

An undercount of Travellers has major implications in providing the denominator for rate calculations. If the figure for 100% of Travellers is inaccurate then all other percentages will also be inadequate. This is one of the reasons why a special count of the Traveller population is part of the National Traveller Health Strategy.

The Census figures confirmed a number of disturbing facts in relation to the age profile and life expectancy of the Traveller community. For example, the Census found that only 3.3% of the Traveller community are over the age of 65 compared to 11.1 of the general population. The Census also confirms that the Traveller population is a young population with 21% of the Traveller population under the age of 14. This means that the average age for Travellers is 18 compared with a national figure of 32.

The Central Statistics Office took a positive partnership approach with Traveller organisations in Census 2002 for which we are grateful. This included discussions around Traveller concerns and ideas, the development of a video and awareness programme aimed at Travellers and training on Travellers with co-ordinators of the Census.



*Census 2002 - still a substantial undercount of Travellers*

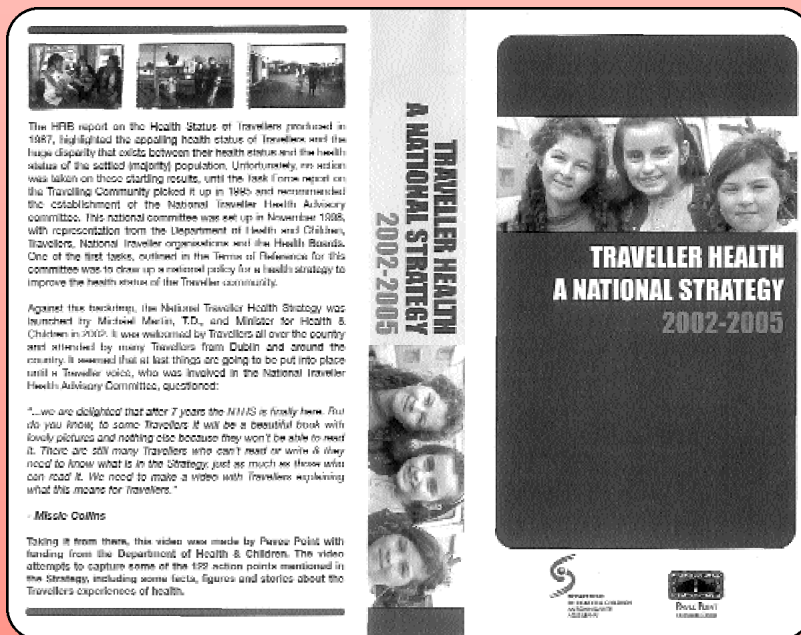
We now urge the Government and the CSO to include a full ethnic question in the next census, such as in Northern Ireland and the UK and many other developed countries. There are an increasing number of non-national ethnic minorities and even Irish citizens who are of minority ethnic backgrounds. A question on nationality does not bring out this type of important information.

In the run up Census 2002, the CSO proposed a full ethnic question, but it was rejected by Government on the grounds that it hadn't been tested. Now is the time to start preparing such a question for the next Census and for other data collection tools. We urge a public debate on this issue.

# Health Strategy on Video

"We are delighted that after 7 years the National Traveller Health Strategy is finally here. But do you know, to some Travellers it will be a beautiful book with lovely pictures and nothing else because they won't be able to read it. There are still many Travellers who can't read or write and they need to know what is in the Strategy, just as much as those who can read it. We need to make a video with Travellers explaining what this means for Travellers," Missie Collins, Pavee Point.

This video is now available free of charge by emailing to [health@pavee.iol.ie](mailto:health@pavee.iol.ie).



## Roma in Ireland

The Roma Support Group and Pavee Point and the Reception and Integration Unit have published a free information sheet on the Roma in Ireland. The brochure gives information on the Roma in Europe as well as looking at particular issues in relation to accommodation and social welfare, health, education, English language and employment.

## Violence against Women

Pavee Point's Violence Against Women Programme has produced a new brochure detailing the programme's aims, objectives and actions. This brochure is free. To get a copy contact the Pavee Point Information Service

