

## Submission From

## Pavee Point Travellers Centre To

## National Economic and Social Forum Project Team on Mental Health and Social Inclusion

National Economic and Social Forum 16 Parnell Square Dublin 1

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Pavee Point Traveller Centre welcomes this opportunity to submit our views to the NESF Project Team on Mental Health and Social Inclusion.

Pavee Point is a voluntary or non-governmental organisation which is committed to human rights for Irish Travellers. The group comprises of Travellers and members of the majority population working together in partnership to address the needs of Travellers as a minority group which experiences exclusion and marginalisation.

The aim of Pavee Point is to improvement in the quality of life and living circumstances of Irish Traveller, through working for social justice, solidarity, socioeconomic development and human rights. Pavee Point believes that health and mental health are basic human rights.

The work of Pavee Point is based on an acknowledgement of the distinct ethnic culture of Travellers, and the importance of nomadism to the Traveller way of life. Innovation has been a key feature of the work done from its starting point based on a community development approach, on an inter-cultural model and on a Traveller/settled partnership. It means working with, rather than for, Travellers in a manner that prioritises Traveller participation. The organisation seeks to combine local action with national resourcing, and direct work with research and policy formulation.

#### **Irish Travellers:**

Irish Travellers are a small indigenous minority group who have been part of Irish society for centuries. They have a value system, language, customs and traditions which make them an identifiable group both to themselves and to others. Their distinctive lifestyle and culture, based on a nomadic tradition, sets them apart from the sedentary population.

Travellers' separateness, partly by choice, enables them to retain their identity as an ethnic group in the face of much opposition and pressure to conform to sedentary society. Their experience of low social status and exclusion- which prevents them from participating as equals in society - is mostly due to the widespread hostility of settled people towards them. This hostility is based on prejudice which in turn gives rise to discrimination and effects Travellers in all aspects of their lives.

".. the circumstances of the Irish Travelling people are intolerable. No humane and decent society, once made aware of such circumstances, could allow them to persist." And... " a uniquely disadvantages group: impoverished under-educated, often despised and ostracised, they live on the margins of Irish society." ESRI Report 1996

Irish Travellers number approximately 7,266 families (DoE 2005 pre-liminary figures, if this figures is multiplied by 5.4 which is the average family size of Travellers during 2002 census it would give us approx 39.236 people) and make up approximately 0.6% of the population. The recent CSO Census 2002 enumerated 23,681 but is probably a low count, given that people were asked to self-identify. It was clear that some Travellers chose not to do so, this was most likely linked to past negative experiences of self- identification.

The CSO 2002 figures show that:

63% are under 25 years of age compared with 37% of total population 42% are aged under 15 years compared with 21% nationally 3% are over 65% compared with 11% nationally.

The difference in demography between the majority population and Traveller community is important to highlight in the planning of future services.

## **Travellers Health Statistics:**

" From birth to old age those at the bottom of the scale have much poorer health and quality of life than those at the top. Gender, area of residence and ethnic origin also have a deep impact."

The Black Report, UK 1980.

The WHO definition of Health states "a complete state of physical, mental and social wellbeing and not merely the absence of disease or infirmity" .. a resource for everyday life not the objective of living; it is a positive concept emphasising social and physical resources as well as physical and mental capacity"

In 1983, the Travelling People Review Body proposed the regular and systematic collection of data on the health status of Irish Travellers. The publication of the 'Travellers Health Status Study - Census of Travelling People 1986', (Barry and Daly 1988:1) and 'The Travellers Health Status Study - Vital Statistics of the Travelling People' 1987, (Barry et al, 1989:2) gave rise to considerable concern about the health status of the Traveller community. These reports found that:

- Fertility rate of Travellers in 1987 was 34.9 per 1,000 more than double the national average and the highest in the European Union.
- Travellers have more than double the national rate of still births.
- Infant mortality rates are 3 times higher than the national rate.
- Traveller men live on average 10 years less than settled men.
- Travellers are only now reaching the life expectancy than settled people reached in the 1940s.
- Travellers of all ages have very high mortality rates compared to the Irish population.
- Traveller women live on average 12 years less than their settled peers.
- Travellers have higher rates of morbidity for all causes and their death ratio is significantly higher than the general population for:
  - Accidents
  - Metabolic disorders in the 0 14 age group
  - Respiratory ailments
  - Congenital problems

90% of adult Travellers are pre/ or illiterate, so much of the health promotion material available is lost because of this. Resources need to be allocated to address this issue in consultation with Traveller organisations.

Since 1987 until now, no National Studies have been conducted on Travellers health. There is little or no research data available on mental health within the Traveller community. The National Traveller Health Strategy 2002-2005 recommended that an All Ireland Traveller Health Needs Assessment and Health Status Study be carried out. Consultation was completed with all stakeholders, on the study design and it has gone to tender. It is envisaged that the study will begin by the end of 2006 or early 2007. The study will address many issues including mental health and well being and the findings will be important in informing policy and service provision for the Traveller community in the future. Travellers and Traveller organisations are participating in all stages of the process and the ownership of the findings by Travellers is important.

"We understand our own people and believe that given the proper support and resources we can begin to improve the health of our community. It is no longer acceptable that only two out of every 100 Travellers lives to 65 years of age" Missie Collins, Community Health Worker, at the launch of the Primary Health Care for Travellers Report by Mr. Michael Noonan, T.D., Minister of Health. 12th June 1996

We urge the NESF Project Team on Mental Health and Social Inclusion to build in the flexibility to incorporate information from national studies, such as, this All Ireland Study, so that the findings can enhance the information base and inform policy in a timely way. Given the absence of information currently available on the mental health status of Travellers, this study could be most useful.

## ISSUES THAT ARE IMPACTING ON THE HEALTH STATUS OF TRAVELLERS:

The issues around health are inextricable linked to issues regarding appropriate accommodation provision for Travellers and further to the social and economic exclusion of this community within contemporary Irish society. The context of Travellers' lives includes the stress generated by living in a hostile society where discrimination is a constant reality, and this is compounded by frequently enforced change in their way of life. These factors impact adversely on Traveller's Health and negatively affect their ability to influence access and experience of health services. A hostile context of racist discrimination has a health impact and has relevance for health provision. The constant erosion of one's self-esteem, might also go far to explain Travellers reluctance to know about, use, or questions service provision.

Health Services need to be flexible in their delivery to respond to the needs of Travellers, but the criticism is made that the provision of culturally appropriate services is expensive and requires additional resources. In the main, it may be just about using your resources in a different way to increase the impact of the service. Additional resources may be necessary in the short term to set up the service but once established they are more effective and reduce cost in the long term.

## RACISM, DISCRIMINATION AND HEALTH

#### **Discrimination and Health**

Discrimination may be direct or indirect. **Direct Discrimination** occurs where a person experiences exclusion or is treated less favourably that another on groups of their membership of a particular group. The grounds on which direct discrimination occurs are listed as gender, marital or parental status, sexual orientation, religion, age, disability, race, colour, nationality, national or ethnic origins including membership of the Travelling community. This form of discrimination is relatively overt and usually involves intent. The Task Force for the Travelling Community 1995, identifies direct discrimination as follows:

"discrimination at the individual level is most common when a Traveller seeks access to any of a range of goods, services and facilities, to which access is denied purely on the basis of their identity as Travellers."

Travellers experience of racism and discrimination can lead to feeling of being a social outcast, having low self-esteem, having lack of pride in one's ethnic identity coupled with anxiety about losing one's identify and experiencing feelings of inferiority. Travellers experience discrimination on a daily basis from verbal and physical abuse; being followed around shops and exclusion from particular services. This constant discrimination has a very detrimental effect on the Health Status of Travellers.

The following findings from surveys conducted will illustrate the reality of discrimination for Travellers and the effects on their self esteem, health and well being.

"In terms of accepting or including Traveller socially or into the community:

- 36% of Irish people would avoid Travellers.
- 97% would not accept Travellers as a member of their family
- 80% saying they would not accept a Traveller as a friend
- 44% would not want Travellers as community members.
- The main reasons for excluding Travellers are perceptions of their way of life/lifestyle and a feeling that Travellers are in some way not socially acceptable (27%)"

Findings from a survey on attitudes which, was carried out with 1,002 adults in January 2000. (Citizen Traveller).

Pavee Point conducted a survey on the Health of Traveller women in 1997 (unpublished), in that study

- 71% of the women reported that they experienced verbal abuse because they were Traveller
- 25% of these included physical violence.
- 10% had taken anti-depressants prescribed by their GP in the previous year.
- 34% of Traveller women interviewed suffered from long term depression compared with a finding of an approx. 9% amongst their settled peers.
- 46% of women described their own general health as "poor" or "fair".

Traveller women are doubly discriminated against because they are women and because they are Travellers. Access to mental health services is particularly problematic for Traveller women, mental health care is uniquely tied to a specific catchment area, based on a residential address, if an address cannot be provided or there is movement between catchment areas access becomes increasingly more difficult.

Some Traveller families do not have access to GPs – often simply because they are Travellers. This excludes families from seeking appropriate primary care. Those who have GPs, may not have the same relationship with the GP that a settled person might have and may not feel comfortable discussing mental health issues. Many Traveller women describe, being given pills for depression, without exploration of other options with GPs. Traveller women use GP services more for their children than themselves, and so there may not be opportunities to discuss personal issues with the GP, and particularly if the GP is male.

As GPs generally do not make visits to halting sites and some families do not have access anyway, many Traveller families end up being forced to use accident and emergency departments "inappropriately", knowing that the service are overburdened but left with little choice. This also reduces the opportunity to identify mental health problems in over- crowded, public emergency departments with a stranger. The Womens Health Study also showed that, GPs and hospital doctors felt levels of depression reported by Travellers was much higher than the general population.

Traveller men with little employment opportunity are often under pressure to provide for their families. They do not generally use health services, and more commonly have their wives describe their symptoms/ailments to GPs for treatment. Again this means opportunistic interventions are missed.

90% of adult Travellers are pre/illiterate so information regarding services are often missed as the information is not accessible to non-readers.

**Indirect Discrimination** is less visible and does not always involve intent. It is most visible in terms of the outcomes for particular groups in relation to services. The clearest example of '**Indirect discrimination**' is the stark inequalities in health outcomes for Travellers as outlined above.

The context of racism experienced by Travellers has therefore a relevance to health policy and provision in that:

- Racism introduces a stress and a crisis into the lives of Travellers that is detrimental to their health and sense of well being.
- Health status outcomes for Travellers are significantly worse than for the majority population and mental health status outcomes unknown.
- -Institutions charged with health policy making and health service provision need to take action to guard against any potential for discrimination in the manner of their operation.

## The provision of culturally appropriate health care for Travellers

Culturally appropriate provision needs to take on board both the tangible and intangible dimensions to culture. It must accommodate not only what people do, but also, their values or what they think and perceive. It must also take account of discrimination at both individual and institutional levels where:

- Procedures and practices can reflect a lack of acceptance of Travellers' culture and
- Travellers can be segregated in the provision of various services
- Legislation, policy making and provision can be developed without account being taken of their potential impact on a minority cultural group such as the Travellers.

"Facing the challenge of the 21st century .. requires a new focus on equality which implies the adoption of a strategic approach for the full integration of women and of people with disabilities, Travellers and other groups experiencing discrimination. It includes the promotion of greater equality of access, participation and outcomes for all marginalised groups in our society." Partnership 2000 for Inclusion Employment and Competitiveness.

## Stigma

There is a strong stigma attached to having mental health problems within the community. This restricts Travellers seeking or availing of any form of mental service because of the perceptions of their community. However there are mechanisms with the Traveller family to deal with issues including issues of wellbeing and mental health. The role of extended family is important and needs to be understood and incorporated into mental health provision. The role of older Travellers in the extended family has traditionally provided informal but culturally appropriate "counselling" in the form of listening and perceived wisdom and this intervention has been an accepted and appropriate response by the community. The close family relationships also means that often there is someone to confide in from within. This guarantees confidentiality as the information remains within the family, but contribute inadvertently to restricting access to more therapeutic interventions (if needed).

Projects such as the Primary Health Care for Travellers Project (currently there are 40 Projects nationally working in partnership with the Health Service Executive), can play a key role. With consultation a more culturally acceptable and accessible service can be given to the community. Going to outsiders for "counselling", particularly when the counsellor is a settled person who may not be aware of Traveller culture, is not an option first considered by most Travellers and so service uptake may be low. More work needs to be done in this area to destignatise mental health within the community and training of mental health professionals around cultural issues and anti racism training is also essential. There are many models for counselling available for example and one which could be appropriate - given the oral tradition of Travellers - could be for example narrative therapy.

#### Prison

Given that there is a disproportionate number of members of the Traveller community in Irish prisons compared to the majority population (Amnesty International Report Mental Illness The Neglected Quarter on Marginalised Groups) - the known effect of prison lifestyle and regime on an individual's mental health, when combined with this high experience of prison committal with the Traveller community, impacts negatively on this community in a more profound way than on the rest of the population.

"There is a gross over-representation of Travellers in forensic admissions... This reflects the excess of Travellers amongst prison committals... These rates suggest that a very high proportion of all Travellers will be imprisoned at some time during their life. This "normalisation" of the experience of imprisonment exposes a high proportion of all Travellers to the adverse health and lifestyle behaviour prevalent in prisons. Prison populations are at a greater risk of developing opiate and other drug dependence disorders, with associated problems. In a more general way, the normalisation of imprisonment is likely to have adverse effects on the expectations and aspirations of children and adults. It adds also to the stigma attached to Travellers as a group....

In any ethnic group or sub-population where imprisonment is so common, it is reasonable to hypothesise for future research that the... impaired ... mental health, may to some extent be caused by imprisonment itself." Irish Travellers and forensic mental health Linehan S, Duffy D, O'Neill H, O'Neill C and Kennedy HG, Ir. J. Psych. Med. 2002; 19(3)

#### **Traveller Accommodation and Living Conditions:**

The Traveller accommodation crisis has been highlighted in Government and other reports over the years. Despite this, many Travellers (approx 939 families D.O.E ) still live on roadside in appalling conditions without access to the most basic services including - water, sanitation and electricity. Many other Travellers live in official accommodation that is poorly serviced and maintained and often situated in unhealthy or dangerous locations. Also many Travellers living in sites live in overcrowded conditions and are doubling up in bays. This is due to fear of eviction from the roadside, this fear relates to The Housing Miscellaneous Act 2002, this act makes trespass a criminal offence

Women are probably most affected by the appalling conditions that they are forced to live in.

"For instance, a high level of psychological distress in Traveller women, which was particularly higher in those with worse accommodation and environmental facilities was found in Heron et al "The Psychological, Social and Cultural perspectives on changing Ireland, Oak Tree Press

There are approx. 939 families still living on the roadside and the lack of facilities, caring for children etc can be extremely difficult for women. The potential for accidents for children where trailers are parked too close to the roadside, and constant illness due to bad living conditions, poverty and marginalisation all impact on the

Traveller women's health. The fear of eviction for families on the roadside is a real and constant pressure especially since the introduction of the Trespass Act.

The breadth and complexities of factors, which determine health and inequalities in health for Travellers illustrate the multitude of sectors with whom it is necessary to work if these issues are to be addressed. Health is therefore an issue for all public policies and must be addressed across all government departments not just the Department of Health and Children. The need for multi- sectoral collaboration to tackle the physical, economic, social and cultural determinants of health has been highlighted in the new National Health Strategy.

## Participation of Travellers and Traveller organisations in health policy, planning and services.

The Task Force on Travellers acknowledge the important role that Traveller organisations play: "They have made a significant contribution to creating the conditions needed for new initiatives to be developed in response to the situation of the Travellers" according to the Task Force they also contribute to "creating a forum where Travellers, with the support of settled people, can come together to formulate their interests and needs and to define a policy agenda that reflects these."

Through facilitating the participation of Travellers in the planning process it will address the assumptions that are made re: people's equality of access to health services. The current planning structure treats everybody equally, this responds to the needs of a certain proportion of the population but it assumes that the population are equal and have equal levels of literacy; language; education; information; and physical and financial access to services, therefore it excludes special needs groups. Health services need to be challenged to be flexible in the delivery of services to respond to the needs of these groups. This can be done by facilitating the participation of Travellers and Travellers organisations in the planning process.

It is important to acknowledge that effective participation by Travellers and Traveller organisations at all levels from needs assessment to evaluation, will require additional resources. These resources may be used to employ community workers, fund capacity building training, primary care projects and administration costs. The Report on 'Equality Proofing commissioned by the Partnership 2000 Working Group, acknowledged the crucial role NGO's can play in policy development and the need to facilitate their participation they stated that:

The National Traveller Health Strategy 2002-2005, drawn up by the National Traveller Health Advisory Committee, makes 122 recommendations. (see Appendix for section on Mental Health) and is an example of where Traveller organisations participation worked. Two recommendations directed to mental health care provision have not yet been implemented and it is imperative that for services to improve and be inclusive these recommendations be acted on as a matter of urgency.

## The provision of targeted and mainstream health responses

Given the poor health status of Travellers a combination of both these strategies are essential, they are not mutually exclusive- a combination of both is essential at this point in time.

Targeting, should be accompanied by the naming of Travellers as a focus for mainstream provision. It is impossible to mainstream without having some targeting initiatives. Targeting creates the conditions for mainstreaming through developing information awareness, analysis and policy positions. Mainstreaming is an essential part of the solution for Travellers health status. However mainstreaming does not mean integration into existing services, it means that services change so they are relevant and accessible to both Travellers and other minority ethnic groups as well as the majority population. It means we have ethnic pluralism in health where health provision is intercultural.

Changing the health status of Travellers requires not just a health care strategy. A much broader ranging strategy is essential. Issues of citizenship and participation; education and employment; poor accommodation and inadequate services; racism, sexism and other forms of discrimination have all to be addressed. Health strategies need to impact on these issues and be coordinated and integrated with them. It requires coordination, information sharing, dialogue and co-operation between a variety of actors and sectors. Multidimensional strategies are required to address the health status of Travellers in a manner that address and removes root cause.

## Recognition that Travellers are not a homogenous group.

Travellers have a lot in common with each other. They share cultural values, beliefs and behaviours. This has to be central to addressing their health needs.

However, there is a need to acknowledge different needs and priorities for different groups of Travellers. Too often interests within the Traveller community are ignored. There is an expectation that all Travellers have the same experiences, needs and desires. We need to move beyond viewing different needs of Travellers by there accommodation status and recognise rather the different interests of young and old Travellers; of Traveller men and Traveller women; of Travellers with a disability etc. We need to focus on what the implications of their different perspectives and interests have for health responses. It is important that there are affirmative action initiatives within the Traveller community for example it is essential that specific policies and resources are targeted at Travellers women and Travellers with mental illness or Travellers with a disability.

# The need for the identification, collection and collation of desegregated data for Travellers in the health services, is particularly important in mental health

Currently, due to the lack of desegregated data it is very difficult to plan provision of health services effectively or to measure equality of access, participation or outcome for Travellers Health. In the Task Force Report it was pointed out in the various sections that the planning process of services was being seriously hampered by this lack of accurate data. The report recommended the putting into place of mechanisms to identify, collate, and analyse data on the access and outcomes for Travellers of the various services including health, education and training, taking cognisance of the data protection implications.

### Recommendations

- A rights based approach should be adopted with regard to mental health and health in general.
- Travellers should be acknowledged and recognised as an indigenous Minority Ethnic Group.
- In recognising the mental health needs of minority ethnic groups and marginalised groups it is important to ensure that appropriate responses to on each groups particular needs are taken into account.
- The recommendations made in the National Traveller Health Strategy should be implemented.
- A holistic approach needs to be adopted if the mental health needs and expectations of the Traveller community are to be met. Interdepartmental collaboration and a multi-disciplinary approach is needed.

## **Culturally appropriate services:**

Sensitivity is needed to ensure a culturally appropriate service is provided to the Traveller community to encourage Travellers to use a service which has not been seen by them as for them to date. It is therefore necessary to consult with the Traveller community on how the service can be more appropriate to their needs.

## **Ethnic Equality monitoring:**

The **ethnic identifier pilot** that was carried out in the Rotunda and Tallaght Hospital should be rolled out nationally as a matter of urgency. The data collected from this could be used in planning services and identifying gaps in provision of health services to Travellers.

## Supporting targeted initiatives.

These should include; Traveller health advocates or community health workers; psychiatric services, specialist public health nurses etc. Traveller health advisors providing resource in appropriate ways. A dimension of this targeting should include partnership between community organisations and the statutory sector is expected to deal with Traveller issues without an adequate and complimentary statutory response.

## **Mainstreaming Travellers and Traveller issues**

This will involve introducing a Traveller proofing mechanism into all dimensions of the health service. Policy development and the implementation of services should be assessed their ability to include Travellers and respond appropriately to their needs. Traveller must be named in all documents relating to health policy. The explicit naming of Travellers as a specific group with specific needs and concerns will go some way to ensuring that they are included in all strategic plans. This recommendation is based on the principle that where Travellers are not named, their distinct needs remain unmet.

## Initiatives to address the specific needs of particular groups of Travellers.

This should include a focus on women; older Travellers; youth, Travellers with a disability, and Travellers with mental illness.

## **Facilitating the employment of Travellers in health services.**

This should include the use of identified positions as recommended by the Task Force with special access criteria applied to certain jobs serving the Traveller community to increase the chances of Travellers taking these posts e.g. child-care workers; refuge staff; as community health workers. Affirmative actions programmes are also required in creating training channels where it would be possible for Travellers to be employed as nurses, doctors etc. These would include having reserved places on courses; special bursaries; awards for training institutions etc.

# Effective Participation of Travellers and Traveller organisations in policy development and the prioritisation and application of resources.

This would involve partnership in the activities of health institutions. It would mean adequately resourcing Travellers and Traveller organisations to participate meaningfully at all levels i.e. needs assessment and prioritisation; planning and design; implementation, monitoring and evaluation. It means creating additional positions for Traveller organisations on regional and national committees, so support can be provided for Traveller representatives to engage effectively in the process, while acknowledging the imbalance in the power relationships. It is only in this way that a truly responsive health service will be achieved, that is a service which is based upon and led by health service user needs.

## Health advocacy needs to be identified as a role for health institutions.

As demonstrated earlier the living conditions and economic circumstances of Travellers particularly affect their health status. A key priority and principle of any Traveller health strategy must be to recognise the role of health institutions as health advocates. This would require a commitment to ensure that the Department of the Environment and the local authorities have a role in developing health/safety standards for the design of Traveller sites (include women and consultation)

### In -service training should be resourced and prioritised

All health professionals as part of their vocational training should have an introduction to Travellers culture and issues. The focus for this training should ensure the development of the skills necessary to provide an inter-cultural service and ensure an anti-racist context.

Specific on going training modules should be developed and supported for health personnel working with Travellers.

Local Traveller groups – should be supported and resourced to ensure their continued involvement in developing partnerships and to further encourage their participation.

## **Education and Awareness Campaigns**

Traveller organisations should be resourced to work with the Traveller community to de-stigmatise "mental health" so that the Traveller community are encouraged to access health services.

A public education and awareness campaign should be resourced to counter the stigma of mental illness. This campaign should emphasise the rights of people in marginalised communities.