

## TRAVELLER HEALTH A NATIONAL STRATEGY 2002-2005







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#### **FOREWORD**



The available data on the health status of the Irish Traveller community shows that they experience a level of health which falls far short of that enjoyed by the general population. This Traveller Health Strategy sets out a clear and practical response to these inequities, with firm proposals for action in line with the policy of social inclusion enunciated in the National Health Strategy, "Quality and Fairness – A Health System for You".

We have put in place new structures recommended by the Task Force on the Travelling Community by establishing a Traveller Health Advisory Committee in the Department and a Traveller Health Unit in each health board. These initiatives exemplify the partnership approach to the development of health services, which is being pursued by the Department, as part of the overall health strategy, bringing together the statutory service providers, voluntary sector service providers and consumers.

The Traveller Health Advisory Committee has identified the factors which adversely affect Travellers' health and this Strategy aims to act on the Committee's recommendations in addressing these difficulties.

The involvement of Travellers themselves in the delivery of health services is considered crucial in bridging the gap between the Traveller Community and the health services.

I would like to place on record my appreciation of the contribution made to the development of this Strategy by the members of the Traveller Health Advisory Committee. I would also like to thank everybody in the Department of Health and Children, the Eastern Regional Health Authority, the health boards and various government departments who participated in the consultation process.

Particular gratitude is due to the members of the Travelling community who, through their representative bodies, have contributed so much to this Strategy.

Micheal Martin T.D.

Minister for Health and Children

Muheal Martin



## SUMMARY OF ACTIONS PROPOSED

- 1. Health service staff, and especially those in functional areas who come into periodic or regular contact with Travellers, will receive appropriate in-service training, prepared in consultation with representative Traveller organisations, on matters concerning Traveller culture and societal attitudes relating thereto. The necessary arrangements will be put in place by June, 2002.
- 2. Health research on Travellers' health needs, founded on sound ethical principles of social research, will be encouraged and supported (and, where relevant such research will be based on codes of practice prepared by the Working Group on Traveller Ethics and Research, proposed in Chapter 5).
- 3. Positive steps will be taken to encourage active partnership and participation of Travellers and their representative organisations in determining health priorities for their community and in the decision-making that accompanies the allocation of resources.
- 4. The planning and provision of health services relating to Travellers will be carried out in partnership with the Traveller community and with due respect for its culture.
- 5. A system of Traveller proofing will be introduced before June 2002 to ensure that Travellers' interests are reflected in all national and regional health initiatives which impact on the health of Travellers.
- 6. Emphasis will be placed on building a community development approach incorporating a permanent role for peer led services and the development of new roles for Travellers within the health services as planners, service providers and promoters, as appropriate.



Discussions will take place between the Department of Health and Children and the Department of Environment and Local Government to examine and determine an appropriate liaison arrangement, including representation from Traveller organisations, between the two Departments with a view to addressing issues of common concern relating to Travellers. The two Departments will be asked to examine issues including the inspection of halting sites, health and safety matters on halting sites and the role of the two Departments, Health Boards and local authorities in addressing these issues and to report within 12 months of the publication of this Strategy.

- **8.** A pilot project will be initiated during 2002 to collect information on ethnicity (including Travellers and other ethnic groups) from the HIPE and/or Perinatal Systems.
- **9.** The results of this pilot will be evaluated with a view to extending identification of ethnicity to other relevant health information systems as part of the implementation programme for the National Health Information Strategy.
- A Traveller Needs Assessment and Health Status Study will be carried out to develop and extend indicators collected in the last survey of Travellers Health Status (Barry, 1987) and to inform appropriate actions required in the area of Travellers' health.
- A working group on Traveller Ethics and Research will be established no later than March 2002 by the Department of Health and Children in conjunction with other relevant agencies. The group will include representation from the Traveller Health Advisory Committee and other appropriate personnel. Its remit will include:
  - 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 this Strategy (including the Needs Assessment referred to above).

- 12. The Department of Health and Children will continue to draw on the ongoing advice of the Traveller Health Advisory Committee in the course of the implementation of this Strategy and in the development of new initiatives.
- An immediate review and survey of the state of implementation of Traveller Health Units and the models developed in each Health Board area will be carried out by the Traveller Health Policy Unit at the Department of Health and Children, in consultation with the Traveller Health Advisory Committee (THAC).
- 14. In addition to the functions listed earlier, each Traveller Health Unit will be required to draw up a regional action plan for the implementation of the proposals in this Strategy within six months of its publication.
- **15.** Specific funding will be allocated to enable Traveller Health Units to implement this Strategy and to progress new health initiatives, in accordance with agreed action plans.
- Funding will be allocated to Traveller Health Units to be used to resource Traveller groups to participate effectively in the units. For example, the funding may be used to employ a Community Worker, engage in capacity building, health training or primary health care training and provide transport and childcare allowances.
- 17. Traveller Health Units will furnish annual reports (including financial information) on progress in the implementation of regional action plans.
- **18.** Appropriate information will be provided to Traveller organisations on the general health status of Travellers, their uptake of services, and other factors impacting on Travellers' health.
- 19. Training on Traveller culture and issues of racism and discrimination will be provided for members of the Traveller Health Unit, in partnership with Traveller organisations.
- **20.** A senior manager will have designated responsibility in each Health Board area, as outlined at 6.8.
- 21. Health Board service plans should be subject to "Traveller proofing" and a template which is currently being piloted in the Eastern region may be of assistance in this connection.

- 22. Health Boards will ensure that health promotion programmes are culturally sensitive and appropriate and recognise the particular constraints under which many Travellers live. The most effective means of ensuring this is to allocate Traveller organisations a central role in both the design and delivery of services.
- 23. The Health Promotion Unit, the Traveller Health Policy Unit, and the Traveller Health Advisory Committee will work with Traveller and other relevant organisations on initiatives to inform the settled community of the detrimental impact which living circumstances and ongoing discrimination have on Travellers' health.
- **24.** Travellers' health should form part of the agenda of the National Health Promotion Forum and Traveller representatives will be invited to join the Forum.
- 25. As outlined in Chapter 5, a Traveller Needs Assessment and Health Status study will be commissioned and carried out as a matter of urgency. The results of this research will inform and influence the provision of health promotion programmes as they apply to Travellers.
- **26.** The National Health Promotion Forum should encourage health proofing of any public policy relevant to Travellers' health.
- 27. Traveller Health Units, in partnership with regional Health Promotion Units, will identify and prioritise existing mainstream health promotion programmes and initiatives which should be Traveller proofed.
- **28.** The priority areas identified as a result of this action should be adapted as appropriate to ensure that they are Traveller proofed.

- Health education programmes for Travellers will highlight the relevance of proper ante-natal and post-natal care. Consideration will be given to providing culturally appropriate antenatal education and care for first time Traveller mothers. Where possible, consideration will be given to providing decentralised ante natal clinics throughout the country.
- **30.** The Maternity and Infant Care Scheme (shared care/GPs and maternity hospitals) will be promoted to encourage earlier ante natal registration. Health promotion material for expectant mothers will be culturally appropriate. Care will be planned jointly with each expectant mother according to her individual needs and wishes commencing in 2002.
- 31. Liaison between maternity units and the Designated Public Health Nurses (see Chapter 11) will be improved to ensure early identification of Traveller mothers, prompt birth notification, more timely communication regarding discharge dates of mother and baby and better follow up. This will commence within six months of publication of this Strategy.
- 32. The need for special tests such as the Guthrie test and Butchler test will be adequately explained to Traveller mothers in the ante natal period. Mothers will be supported and encouraged to stay for an appropriate period of time in hospital following birth so that the full range of post natal services is availed of.
- 33. Greater access to and uptake of family planning and sexual health services will be encouraged by Health Boards through improved primary care services.
  Where appropriate, special Health Board clinics should be held at which the necessary services can be provided.
- 34. Peer led educational and awareness programmes on family planning and sexual health should be considered by Health Boards, as should other means of communication such as videos, which may be more appropriate to Travellers' needs than written materials.
- **35.** The opportunity should be taken, in the context of Travellers availing of post natal services, to discuss women's future contraceptive needs.
- 36. Access to women's refuges in each Health Board area should be monitored to ensure that no barriers exist for Travellers and that they are inclusive of Travellers' needs. Attitudes and behaviour towards domestic violence should be a key part of focused health promotion programmes.
- **37.** Travellers and Traveller organisations will be represented on all national and regional steering groups addressing the issue of violence against women.



- **38.** Any research projects undertaken on the issue of violence against women will include a Traveller dimension following approval by the Traveller Ethics and Research Working Group.
- **39.** Traveller organisations promoting special initiatives addressing the issue of violence against women will be supported.
- **40.** Refuges will be encouraged to develop and adopt anti racist codes of practice and to provide in service training in anti racism and interculturalism.
- **41.** Initiatives to work with Traveller men perpetrating violence will be supported.
- **42.** Traveller organisations will be funded to train and employ Traveller women as refuge workers and counsellors.
- 43. The Traveller Needs Assessment and Health Status Study, proposed in Chapter 5, will include specific references to the health needs of Traveller men. The findings of the study will inform the provision of culturally appropriate initiatives on Traveller men's health.
- 44. Primary Health Care for Travellers Projects will be developed in conjunction with Traveller organisations in all Health Board areas where there is a significant Traveller population by the end of 2005. The Department of Health and Children will provide funding to allow for the freeing up of staff and other resources on the part of appropriate organisations in order to implement a suitable strategy for replication of the Projects in relevant areas.
- **45.** Each Primary Health Care for Travellers Project will have two Co-ordinators, a relevant health professional, employed by the Health Board and a Community Health Worker, employed by the Traveller organisation.
- 46. In developing the Primary Health Care for Travellers Projects there will be an emphasis on flexibility and innovation in order to respond to differing circumstances and differing health needs as identified by Travellers in each area.
- The projects will be periodically evaluated and progress reports made available to the Traveller Health Advisory Committee at the Department of Health and Children.
- **48.** As they are developed, the Projects will be used as a resource to train Health Board staff and other health professionals in anti-racism skills, Traveller culture and good practice in addressing Traveller health needs.
- **49.** Commencing in 2002, the Department of Health and Children will support an annual conference to share experience and learning of Primary Health Care for Travellers Projects.



- 50. The Department of Health and Children will establish a Working Group comprised of Traveller organisations, members of the Traveller Health Advisory Committee, the Irish College of General Practitioners, and Public Health Nurses working with Travellers. The group will draft the content and agree the design of a durable and user friendly patient and family held record to be used by all Health Boards.
- 51. The group will be convened within three months of publication of this Strategy and report to the Department with its recommendations after a further six months. Introduction of the new record on a nationwide basis should commence not later than June 2003.

- **52.** Health Boards and the ERHA, in liaison with Traveller representative organisations, will monitor access by Travellers to general practitioner services on a regular basis and will report annually on developments and progress in this regard.
- 53. In line with the provisions of the Equality Act, in any future review of the General Medical Services (GMS) Scheme contract, the terms of the contract will be expressed so as to limit the circumstances in which a general practitioner who is a contracted GMS Scheme doctor can refuse to register a Traveller patient.
- The Department of Health and Children, the ERHA and the Health Boards will ensure that the criteria used in determining future funding support for GMS projects generally take account of the needs of Travellers and have regard to the extent to which any service improvement benefits Travellers.
- **55.** The development of existing 'GP out of Hours' projects being piloted should have equal regard to Travellers' needs.
- **56.** Health Boards' Primary Care Units should be represented on Traveller Health Units in each area. Such representation will facilitate greater liaison between the Primary Care Unit and the Traveller Health Unit with regard to General Practice issues relevant to Travellers.
- The Primary Care Unit manager should be a member of the Traveller Health Unit. Such membership will allow the manager to advise the Traveller Health Unit of developments in general practice that are relevant to Travellers and to be advised by them of matters in general practice that are of concern to Travellers.
- **58.** To ensure that Travellers benefit from the future potential of information technology in general practice, an appropriately focused pilot scheme will be designed and introduced, as soon as practicable. This will involve the identification of Travellers on these pilot projects in the context of their ethnicity.

- 59. The future development of general practice is to be quality based. Accordingly, it is essential that the criteria to be used in establishing quality measures should have regard to the needs of Travellers if the quality concept is to be truly inclusive.
- **60.** Health Boards will be encouraged to put special arrangements in place to ensure that the medical card scheme is administered in a culturally appropriate manner which addresses the needs of Travellers who avail of the scheme.
- 61. The Department of Health and Children will work with the Irish College of General Practitioners (ICGP), the University Departments of General Practice and Traveller organisations in promoting any educational, training or promotional programmes designed by them to highlight issues of Travellers' health at undergraduate, postgraduate, vocational or continuing medical educational levels. As a first step, additional study leave will be granted to any general practitioner wishing to take part in the ICGP's training module in Traveller Culture and Health Needs.
- **62.** A health education module will be developed and implemented in partnership with Traveller organisations to increase Travellers' awareness of the range of services that are, at present, available in general practice and of the desirability of availing of these services when required. This module will need to take into account any existing barriers to meaningful access and utilisation of service.
- 63. Applications for research or education on matters of Travellers health status or needs will be facilitated under the GMS Research and Education Fund. It should have regard to the code of practice on research which is to be prepared by the Working Group on Traveller Ethics and Research.
- 64. A review will be carried out of the prescribing processes and practices used by GP's for the Traveller community. (This review will be completed within 12 months of publication of this document.)

- Health Boards will be encouraged to appoint designated Public Health Nurses to work with Travellers, in accordance with guidelines set out in Chapter 11.
- 66. Public health nurses recruited or designated to work with Travellers must have an interest in the area, be experienced and be provided with adequate training in Traveller culture, community development skills, anti-racist skills and in health issues specific to Travellers.
- 67. In instances where Travellers have difficulty in accessing postal services, they will have the option of nominating their designated PHN, Community Health Worker or their local Traveller organisation to be sent copies of correspondence relating to appointments (within the bounds of patient confidentiality) between secondary care and specialist services and Traveller families under their care.

- 68. Travellers will continue to be designated as a Special Needs Group in relation to dental services.
- **69.** Access to dental services will be improved through more widespread provision of special services and through increasing the acceptability to Travellers of mainstream services.
- 70. While maintaining the right of any Traveller to access mainstream services under the Dental Treatment Services Scheme, special clinics, with an emphasis on care for the whole family, will be designated and promoted in areas where there is a significant Traveller population. These clinics should be operational by the end of 2002.
- 571. Special clinics will be timed to cater for particular needs in specific areas. Given the family focus in these clinics, the opportunity should be used by the Oral Health Care Promoter to hold parallel sessions for mothers of young children.
- **72.** A dental register and recall system will be set up in each community care area to be operated jointly by the designated special needs dental team in conjunction with Traveller Community Health Workers / Designated Public Health Nurses.
- **73.** A dental nurse from each special clinic will be designated as a liaison person in respect of Travellers. His / her role will include liaison with Designated Public Health Nurses and /or with Traveller Community Health Workers on the appointment reminder system and the operation of the dental register and recall system.
- **74.** On-site screening will be extended as more special clinics are set up.
- **75.** Traveller children who are not accessing the school dental service will be identified and arrangements made through the Traveller Community Health Workers from the Primary Health Care for Traveller Projects to encourage follow up and screening.
- **76.** In addition to oral health promotion initiatives developed and co-ordinated at national level, each Health Board, through the Oral Health Promoter and the Primary Health Care Projects will develop programmes and materials suitable for local use.
- 77. The promotion of oral health will be a core objective of Primary Health Care for Travellers Projects. Traveller Community Health Workers working with designated Oral Health Promoters in each area will be responsible for co-ordinating oral health promotion initiatives including improving access to special and mainstream services.
- **78.** A baseline survey of the Traveller population assessing oral / dental health, level of access to services and, if possible, the extent to which fluoride intake is adequate or not, will be undertaken before the end of 2002 and repeated every 10 years. For this survey to be effective and statistically valid, it will need to be carried out with the full co-operation and involvement of Traveller organisations.

- 79. The Department of Health and Children will seek and act on the advice of the Health Boards and the Traveller Health Advisory Committee on issues relating to the delivery of ophthalmic and aural services to Travellers.
- **80.** The Traveller Needs Assessment and Health Status Study proposed in Chapter 5 will include consideration of Travellers' awareness of mental health services and will also explore the effectiveness of existing services.
- 81. Primary Health Care for Travellers Projects will be involved in a programme of education/information regarding the psychiatric services including the development of appropriate information packs.
- **82.** Formal links will be created between community psychiatric services and Traveller organisations in each Health Board area to facilitate early intervention.
- 83. Specific training in Traveller identity and culture will be provided to mental health service providers in order to ensure that such cultural factors are fully understood in meeting the needs of Travellers in this sensitive area.
- 84. The Department of Health and Children will establish a national working group, representing statutory and voluntary mental health service providers, Travellers and Traveller Organisations to explore culturally appropriate models of mental health services for Travellers.
- **85.** Early intervention services for traveller children with an intellectual disability will be designed and delivered in a culturally appropriate way.
- **86.** Training and support will be provided to parents of children with an intellectual disability, including increased access to respite and day care services.
- 87. A programme of outreach services developed to support Traveller families with special needs in the area of Metabolic Disorders, will be recognised by the Intellectual Disability Services. Shared care for some conditions (eg. Galactosemia) will be provided by the national paediatric units and local community services.
- **88.** The national research into Traveller Needs and Health Status proposed in chapter 5 will include an estimate of the numbers of Travellers with a disability and the appropriateness of current service provision.
- 89. In 2002 The Department of Health and Children will develop and monitor an initiative to ensure that the services for those with a disability are sensitive and responsive, in a culturally appropriate way to the special needs of Travellers.



- **90.** The Department of Health and Children will consult with the Department of Education and Science regarding the teaching of sign language to parents of Traveller children who have a hearing disability.
- **91.** Primary Health Care for Travellers Projects will develop health education modules for the Traveller community to inform them of the range of services available for those with special needs and disabilities.
- **92.** New approaches to support services will be developed including the training and employment of Traveller care assistants and home helps.
- **93.** The needs of the individual and the family must be taken into account when planning services for Travellers with a disability. A programme will be developed to ensure that individuals with a disability are supported where appropriate to remain within their home environment.
- **94.** The liaison mechanism with the Department of Environment and Local Government proposed in Chapter 4 will address and monitor the issue of appropriate accommodation for Travellers with disabilities.
- **95.** A National Working Group will be established consisting of a Speech and Language Therapist, Psychologist, Aural Health professionals, and representatives from the THAC. The Working Group will address the following recommendations:
  - The inclusion of a question in the Needs and Health Status study on barriers to access, appropriateness and utilisation of these services by Travellers.
  - The development and piloting of culturally appropriate therapeutic and assessment materials for Travellers.
  - the development of new initiatives to increase the uptake of aural screening services during the first two years of a Traveller child's life and the implementation of a national training programme in the pre -school setting targeted at the stimulation of speech and language skills in pre-school children.
- 96. Taking due account of existing legal provisions, the Department of Health and Children will examine the implications of providing a designated Social Work Service for Travellers in each Health Board Area with a significant Traveller population. The role of these social workers will be broader than Child Care commitments and will include an involvement in a multidisciplinary team comprising additional Social Workers, Public Health Nurses, Traveller Community Health Workers, Childcare workers and Family Support workers. Traveller organisations, Area Medical Officers, Designated Family Therapists and counsellors will be consulted as appropriate. The objective of this team will be to provide early identification, support and intervention for Traveller families 'at risk'.



- **97.** Culturally appropriate preventive services such as youth projects, family support projects and parenting courses should be provided.
- **98.** The recommendations of the Working Group on Foster Care ( referred to at paragraph 13.12 of the main text ) will be implemented as soon as possible.
- 99. Traveller children will be identified on childcare and fostering records where appropriate to identify the numbers of Traveller children in care and facilitate the tracking and monitoring of these children through the care system.
- **100.** Recommendations from the research currently being conducted in the Eastern region by the Traveller Health Unit into the experience of Travellers in care will be considered.
- **101.** Each Health Board will develop an age profile of its local Traveller population.
- **102.** Older Travellers will be identified on all health record systems.
- **103.** The care of older Travellers will be included as part of the caseload for designated PHNs for Travellers.
- 104. Guidelines for Community Welfare Officers by the Department of Social, Community and Family Affairs in pursuance of a commitment in the PPF will explain provision in relation to awareness of Traveller culture and the principles of anti racism.
- **105.** CWOs in border areas will be mindful of the implications of cross border nomadism by Travellers on access to services in the two different jurisdictions.
- 106. Travellers' needs will differ from those of the settled community and specific guidelines governing the issue of discretionary payments to Travellers will be developed in consultation with Traveller organisations.
- **107.** Clear and relevant information on discretionary payments will be made available to Travellers in an accessible format.
- 108. The Department of Health and Children will liaise with the Department of Social, Community and Family Affairs to address any other issues concerning the administration of discretionary services to Travellers.
- 109. The Department of Health and Children will enter into dialogue with the relevant authorities, including the National Drugs Strategy Team to ensure that any research into Traveller health and lifestyles will include research into the pattern of use of alcohol and drugs. The involvement of the Traveller Specific Drugs Initiative and Traveller organisations is critical to the success of this research.



- **110.** Service providers in the substance misuse area will be made aware of the results of the research proposed above and the importance of the inclusion of Travellers in the planning and delivery of services.
- 111. Travellers will be involved in the design and delivery of targeted substance misuse prevention programmes. Critical to this will be the central involvement of the Traveller Specific Drugs Initiative, Traveller organisations and the Traveller Community Health Workers
- 112. Appropriate training will be provided in each Health Board area for Health Board professionals, support workers and Travellers (including Traveller Community Health Workers where they exist) around education and preventative approaches to substance misuse.
- 113. Local and regional Drug Task Forces, in preparing, implementing and updating their plans will examine issues, including Traveller drug misuse, which should be dealt with in an integrated and coherent manner.
- **114.** The Department of Health and Children will take account of the findings of the The Traveller Consanguinity Working Group.
- 115. The Department of Health and Children will examine the possibility of making genetic screening and counselling services available in all Health Board areas where there is a significant Traveller population.
- 116. Vigorous efforts will be made to ensure that Traveller babies receive the full range of neonatal metabolic screening. If this involves longer stays in hospital post-partum to ensure that babies are not lost to follow up, this will be considered. (See also Chapter 8 regarding maternity services).
- 117. Designated Public Health Nurses, Traveller Community Health Workers and other relevant personnel will receive training in nutrition as it relates to the treatment of metabolic disorders in order to provide information and support to families where a member suffers from a metabolic disorder.

- 118. Hospital staff who regularly come into contact with members of the Traveller community will receive training and education in intercultural and anti discrimination practices and in particular Traveller perspectives on health and illness.
- **119.** The feasibility of appointing appropriate liaison persons in hospitals to address issues relating to Traveller use of hospital services will be examined.
- **120.** As Accident and Emergency departments make greater use of general practitioner and nurse led triage, every effort will be made to re-direct or treat Traveller patients at the most appropriate level.
- 121. As a means of reducing the pressure on Accident and Emergency Departments from inappropriate out of hours consultations, recent developments in relation to improved out of hours GP cover will be examined.
- **122.** Health promotion programmes for Travellers will include a module covering the appropriate use of hospital services including accident and emergency, in patient and out patient services and maternity services.







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TRAVELLERS ARE PARTICULARLY DISADVANTAGED IN TERMS OF HEALTH STATUS AND ACCESS TO HEALTH SERVICES.

#### **Reasons for a Traveller Health Strategy**

#### 1.1

Travellers are a distinct minority group of Irish people. They differ from the general population in many respects including their life-style, their culture and their treatment by society. In the Ireland of today, the Traveller community continues to experience high levels of social exclusion and disadvantage – a situation which requires an urgent, planned response.

#### 1.2

In the current climate of national economic success, one aspect of Travellers' lives stands out starkly in terms of disadvantage. For many years and for a variety of reasons, the Traveller population has experienced a level of health which falls far short of that enjoyed by the general population. This has serious implications for our strategic approach to the planning and delivery of an equitable health service in accordance with national policy. This Traveller Health Strategy explores these implications and provides a clear statement of policy which focuses on the underlying problems associated with the poor health status of the Traveller population and sets out a realistic and practical plan for specific improvements in that status.

#### **Background to the Strategy**

#### 1.3

This Strategy responds to one of the key recommendations of the Report of the Task Force on the Travelling Community, which was published in 1995. The Task Force identified the provision of health services and in particular, questions associated with access to and utilisation of these services, as being of major concern to the Traveller community.

The Task Force recommended that a Traveller Health Advisory Committee should be appointed by the Minister for Health and that its brief should include the drawing up of a national strategy to improve the health status of the Traveller community. Following its establishment at the end of 1998, the Traveller Health Advisory Committee (THAC) began preparing draft proposals for a national health strategy for Travellers. The Advisory Committee's recommendations were submitted to the Department of Health and Children at the end of 2000 and the Department has relied heavily on those recommendations in its formulation of this Strategy.

#### 1.5

The Strategy also takes particular account of the key principle of equity in the provision of healthcare. Current health policy recognises that the pursuit of equity must extend beyond the question of access to treatment and care.

"THERE IS A PARTICULAR OBLIGATION UPON THE HEALTH SERVICES TO PAY SPECIAL ATTENTION TO GEOGRAPHIC AREAS OR POPULATION GROUPS (SUCH AS TRAVELLERS) WHERE THE INDICATORS OF HEALTH STATUS ARE BELOW AVERAGE.....
THERE WILL BE A SPECIFIC POLICY OF TARGETING RESOURCES TOWARDS AREAS OR GROUPS WITH LOW HEALTH STATUS AND GIVING THEM PRIORITY IN THE DEVELOPMENT OF SERVICES"

(Shaping a Healthier Future, 1994).

#### 1.6

The future direction of health services in Ireland has been set out in a major new Health Strategy which has just been published ( Quality and Fairness – a Health System for You - 2001 ) and which outlines the context in which this Traveller Health Strategy will operate. The approach to Travellers' health must also have regard to various other policy documents dealing with particular aspects of the nation's health. While these are not aimed solely at Travellers, they put forward strategies for the planned development of services which are of significance to Travellers, as they are to the settled population, given that Travellers should be entitled to a core set of health care services on the same basis as the settled population.

These important policy documents, which should be read in conjunction with this Strategy, include the National Children's Strategy, the National Health Promotion Strategy, the National Cancer Strategy, and the Cardiovascular Strategy. In planning and providing for the special health needs of Travellers, linkages and networks need to be maintained with all service planners in order to keep health services for Travellers in line with overall regional and national policy, thus preventing further marginalisation of Travellers. Where possible, the aim should be to provide integrated services with a positive bias towards Travellers rather than a separate service, with a further enhancement of mainstream provision by designated or specialist services in some key areas.

#### 1.8

Travellers are particularly disadvantaged in terms of health status and access to health services. Generally speaking, they suffer poor health on a level which compares so unfavourably with the settled community that it would probably be unacceptable to any section thereof. Travellers die at a younger age than the population in general.

#### 1.9

Among the most important factors contributing to this situation are social exclusion, the influence of a harsh living environment and racism. This Strategy identifies how health planning and health services can play their part in the wider policies which are aimed at eliminating these factors. More particularly the Strategy describes a number of key aspects of Travellers' health which need to be addressed if an improvement in Travellers' health status is to be brought about. It also sets out specific proposals to tackle these issues and in so doing, takes account of the special considerations which apply in relation to Travellers' access to health services and their utilisation thereof.

#### 1.10

The Traveller community suffers other significant disadvantages in comparison to the general population. Social exclusion resulting in poverty, unemployment and educational disadvantage conspires against achieving improvements in health status. For example, up to 80% of adult Travellers are unable to read. This has a serious impact on the effectiveness of health promotion, as well as on simple everyday tasks such as filling out forms for medical card applications or understanding instructions on prescription medicines.

In the past, the health services have responded in a fragmented and often inappropriate manner to the special needs of Travellers. This has been compounded by a lack of awareness among Travellers of the value of preventative services in particular. In combination, these two factors have resulted in Travellers being at a disadvantage when it comes to availing of the health services. Examples include low immunisation rates and poor utilisation of maternity services and women's health services.

#### 1.12

Discrimination on an individual and institutional level is also a factor in the lack of an effective response to Traveller health needs. In the past, the official policy of assimilating Travellers into the settled community is likely to have been at the root of much of the institutional inertia in terms of developing Traveller specific services and special initiatives. Significant progress in the last decade in terms of equality legislation, health policy and recognition of Traveller culture is now providing a platform for a more enlightened response. Prior to the early 1990s, special provisions for the health needs of Travellers did not feature significantly in the health services. Since that time, however, various Traveller organisations and health agencies have been looking at new approaches to tackling the issue of Traveller health status. This has resulted in a number of special initiatives being taken which are aimed at facilitating a better link-up between the health services and the Traveller community. This Strategy proposes to build on these initiatives.

Travellers are particularly disadvantaged in terms of health status and access to health services. Generally speaking, they suffer poor health on a level which compares so unfavourably with the settled community that it would probably be unacceptable to any section thereof.

Travellers die at a younger age than the population in general.



CORE VALUES AND PRINCIPLES

THIS STRATEGY RE-AFFIRMS
THE RIGHT OF TRAVELLERS
TO APPROPRIATE ACCESS TO
HEALTHCARE SERVICES THAT TAKE
INTO ACCOUNT THEIR PARTICULAR
NEEDS, CULTURE AND WAY OF LIFE...

The formulation of any policy response to the issue of Travellers' health must be based on a consideration of the present situation and an objective assessment of the extent to which the present levels of service provision fall short of meeting existing needs. This Strategy identifies and proposes ways in which service provision can be arranged to meet the requirements of appropriate healthcare for Travellers.

#### 2.2

Underlying the proposed policy response must always be a core value, which gives rise to a set of guiding principles that act as a structure for policy decision-making and operational action. In this regard, the core value is identified as achieving equity in healthcare service provision. It requires acceptance that equity is based not just on equality of access but on equality of participation and outcome and that the particular needs and culture of Travellers require an innovative approach to health service planning, promotion and delivery, while making the best use of the contribution that Travellers themselves can make to this process.

#### 2.3

It is recognised that even if the core value is fully accepted, the measures actually undertaken and the resources actually allocated will ultimately determine whether it is ever achieved. As a guide, therefore, to the decisions which need to be made and the actions taken, the following general principles (arising from the core value) have been borne in mind in preparing this Strategy.

#### 2.4

Given the unacceptably wide gap between the health status of Travellers and that of the settled community, this Strategy re-affirms the right of Travellers to appropriate access to healthcare services that take into account their particular needs, culture and way of life and, accordingly, action to promote the health and welfare of Travellers will be afforded a high priority.

The focus of the new approach to Travellers' health needs must be on equality of outcome as well as equality of access to, and participation in, services beginning from the position that there is a greater need for healthcare for Travellers at present, given their poor current health status. Aiming for equality of participation (i.e. same service for same service needs) does not guarantee equality of outcome (i.e. the state of health or well – being following the provision of the service). For this reason, particular attention must be paid to monitoring outcomes during the course of implementing this Strategy.

#### 2.6

Acknowledging that mainstream health service provision has not met the needs of Travellers up to now, it is clear that continuing mainstream service provision must be accompanied by Traveller specific programmes that expressly address and target the particular health needs of Travellers. This will be supported by flexibility in health services' infrastructures and facilities that have regard to the particular needs of Travellers and that place a major emphasis on environmental health issues affecting Travellers.

#### 2.7

To ensure adherence to these principles in the course of implementing this Strategy, it is important to make clear the relevant responsibilities of the Department of Health and Children, the Traveller Health Advisory Committee, and the Traveller Health Units at Health Board / Eastern Regional Health Authority (ERHA) level. Sufficient resources will be made available to those bodies to make the proposals in this Strategy a reality.

#### 2.8

The creation and maintenance of a positive awareness among all those involved in the health services of the cultural traditions and distinct identity of the Traveller community will be necessary in order to ensure respect for that identity and those traditions. This will involve the provision of appropriate in-service training, in consultation with representative Traveller organisations, on matters concerning Traveller culture and societal attitudes relating thereto.

Health research on Travellers' health needs, founded on sound ethical principles of social research and agreed codes of practice, will be encouraged and supported.

#### 2.10

Active partnership and participation of Travellers and their representative organisations will be encouraged in determining health priorities for their community. All planning and provision of health services relating to Travellers will be carried out in this spirit of partnership and with respect for the Traveller community and its culture.

#### 2.11

Building a community development approach incorporating a permanent role for peer led services and the development of new roles for Travellers within the health services as planners, service providers and promoters, as appropriate, is essential.

The focus of the new approach to

Travellers' health needs must be on
equality of outcome as well as equality of
access to, and participation in, services
beginning from the position that there is
a greater need for healthcare for
Travellers at present, given their poor
current health status.



# CHAPTER 3

ETHNICITY, CULTURE AND TRAVELLERS' HEALTH

THERE IS NOW RECOGNITION AT OFFICIAL LEVEL THAT TRAVELLERS ARE A DISTINCT MINORITY WITH THEIR OWN CULTURE AND BELIEFS AND MOST IMPORTANTLY THAT THEY HAVE A RIGHT TO HAVE THEIR CULTURE RECOGNISED IN THE PLANNING AND PROVISION OF SERVICES...

The Task Force on the Travelling Community devoted a chapter of its report to the topic of culture. It stated that:

"EVERYBODY HAS A CULTURE. IT IS THE PACKAGE OF CUSTOMS, TRADITIONS, SYMBOLS, VALUES, PHRASES AND OTHER FORMS OF COMMUNICATION BY WHICH WE CAN BELONG TO A COMMUNITY. THE BELONGING IS IN UNDERSTANDING THE MEANINGS OF THESE CULTURAL FORMS AND IN SHARING VALUES AND IDENTITY. CULTURE IS THE WAY WE LEARN TO THINK, BEHAVE AND DO THINGS."

### 3.2

This provides a challenging framework within which to define the relevance of Traveller culture to the design and delivery of health services. Traveller culture has both tangible and intangible elements. The tangible elements are associated with behaviour and tradition. They can be seen in Traveller nomadism, in the way Travellers organise their economic activity and in the family structures within the Traveller community. The intangible elements are associated with values and beliefs. These are less visible and harder to define at any particular moment. Yet they are fundamental because they are at the root of different behaviours and they are the key to how issues are perceived or addressed.

#### 3.3

Traveller culture and identity have a relevance to health policy and the provision of health services. They play an important part in:-

- Shaping Travellers' definitions of health, perceptions of illness and responses to illness.
- Influencing the manner in which Travellers take up health services.
- Challenging health policy and provision to be accessible and culturally appropriate to Travellers if equitable health status outcomes are to be achieved.

The Task Force placed particular emphasis on the impact which racial discrimination has on Travellers' health and its relevance to health provision. The Task Force identified this discrimination as happening both at the individual or interpersonal level and at the institutional level. On an individual level, discrimination can involve verbal and physical abuse and exclusion from particular services, events or places. On an institutional level, the Task Force highlights three potential means by which discrimination can occur. These are:-

- Where procedures and practices can reflect a lack of acceptance of Travellers' culture and identity
- Where Travellers can be segregated in the provision of various services.

  (It is important in this context to distinguish between segregation which is imposed and provision which is designed to respond to a particular need where participation is by choice).
- Where legislation, policy making and provision can be developed without account being taken of their potential impact on a minority cultural group such as Travellers.

#### 3.5

Institutional discrimination often happens without intent, being based in many cases on a benign paternalism, or "we know best" attitude. However, it is important to underline how far Government policy has come in terms of official attitudes to the Traveller community. From a position where the policy in the 1960's was to assimilate Travellers into the settled community, there is now recognition at official level that Travellers are a distinct minority with their own culture and beliefs and most importantly that they have a right to have their culture recognised in the planning and provision of services. This point is of critical importance. If we as a society recognise and accept the rights of minority groups then we must be prepared to ensure that services (in this case health services) are responsive to Travellers especially in terms of their nomadic lifestyle.

Throughout the full range of health services there are considerable difficulties with regard to their provision and utilisation in relation to Travellers. Much of this relates to difficulties on the part of health services in taking account of the tangible and intangible differences in Traveller culture referred to at 3.2. Tangible differences include nomadism which for the majority of Travellers, is a basic part of their culture, although it takes many forms among the Traveller community. It has implications for the provision of health services. It also has implications for the maintenance of medical records, communication and correspondence with patients and eligibility for medical cards.

#### 3.7

Another tangible aspect of Traveller culture is the role of the extended family. This has implications for hospital visiting arrangements for Traveller families, for families accompanying patients as well as for organising appointments on a family basis.

#### 3.8

The manner in which Travellers organise their daily lives has implications for the timing of appointments and the localisation of provision.

#### 3.9

The more intangible elements such as values, beliefs and perceptions pose a different set of challenges to the health services. Communicating across the cultural divide is a skilled process where members of the Traveller community have a vital role to play. The issue here is not just about provision of culturally appropriate information about health services but also about empowerment and supporting Travellers to take control of their own situation. Peer - led initiatives have a particular role to play in this regard. An example of this type of initiative is discussed in more detail in Chapter 8.

#### 3.10

Today's stark picture of Travellers' health status and access to services presents the Department of Health and Children and health agencies with considerable challenges. This document proposes a range of actions which seek to meet these challenges in a manner which takes account of Traveller culture and the need to work in partnership with Travellers to address their health needs. It is important to create and maintain a positive

awareness, among health service providers, of the cultural traditions and distinct identity of the Traveller community, in order to ensure that this identity is respected.

### **ACTION PROPOSED:**

- Health service staff, and especially those in functional areas who come into periodic or regular contact with Travellers, will receive appropriate in-service training, prepared in consultation with representative Traveller organisations, on matters concerning Traveller culture and societal attitudes relating thereto. The necessary arrangements will be put in place by September, 2002.
- Health research on Travellers' health needs, founded on sound ethical principles of social research, will be encouraged and supported (and, where relevant such research will be based on codes of practice prepared by the Working Group on Traveller Ethics and Research, proposed in Chapter 5).
- Positive steps will be taken to encourage active partnership and participation of Travellers and their representative organisations in determining health priorities for their community and in the decision-making that accompanies the allocation of resources.

- The planning and provision of health services relating to Travellers will be carried out in partnership with the Traveller community and with due respect for its culture.
- A system of Traveller proofing will be introduced before September 2002 to ensure that Travellers' interests are reflected in all national and regional health initiatives which impact on the health of Travellers
- Emphasis will be placed on building a community development approach incorporating a permanent role for peer led services and the development of new roles for Travellers within the health services as planners, service providers and promoters, as appropriate.



# CHAPTER 4

FACTORS INFLUENCING TRAVELLERS' HEALTH

THE OCCURRENCE OF SUDDEN INFANT DEATH SYNDROME (SIDS) AMONG TRAVELLER FAMILIES IN 1999 WAS TWELVE TIMES THE NATIONAL FIGURE (8.8 VS 0.7 PER 1000 LIVE BIRTHS)...

#### **Some Relevant Statistics**

#### 4.1

While this document articulates a specific response which is targeted at the special health needs of Travellers, its preparation has been subject to some statistical uncertainties in relation to Travellers. Principal among these have been firstly, uncertainty as to the size of the Traveller population and secondly, uncertainty regarding the precise health status of Travellers.

The Equal Status Act (2000) defines the Traveller Community as follows:

"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."

## 4.2

The 1996 Census is now widely acknowledged to have grossly underestimated the number of Travellers in Ireland at 10,891. The census did have a "Traveller" question but it was for the enumerator rather than the census participant to respond and the criteria which were established for Traveller identification did not fully reflect the definition at 4.1 above. All Travellers in housing were excluded and this resulted in a significant undercounting of Travellers.

#### 4.3

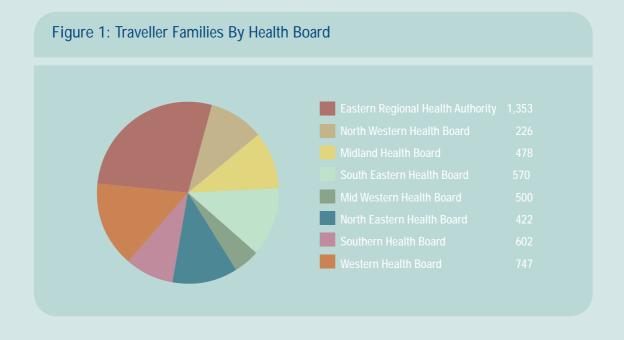
This document does however make some references to the 1996 Census data. It should be borne in mind that because the data was skewed in that it counted only Travellers in halting sites, the data may be biased in terms of the age profile of Travellers (since younger Traveller families tend to be more mobile because their accommodation options are more limited).

The 2000 Department of Environment and Local Government / Local Authority count of Traveller families shows that there were 4,898 Traveller families in 2000. Based on an average family size of 4.9 people ( CSO Census of Population 1996 ), this suggests that the population of Travellers is approximately 24,000.

# **Geographical Distribution**

#### 4.5

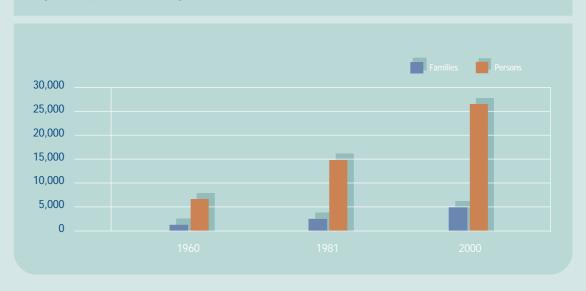
The total number of Traveller families in 2000 was 4,898. Figure 1 shows the geographical distribution of these families by Health Board area.



#### 4 6

Figure 2 indicates that the population of Travellers in Ireland has grown more than fourfold in the past 40 years.





Ref: ESRI, Department of the Environment and Local Government, Central Statistics Office

Some statistics which are indicative of the lifestyle of Travellers are worth noting, including those relating to age distribution ( see Fig. 3 beneath )

Statistics from 1996 showed that Traveller families had 3.5 children on average, in comparison to 1.8 children for the general population (CSO, Census of Population, 1996)



Fig. 3: Age Distribution

The 1996 Census indicated a marked difference between the age structure of the Traveller community and that of the country as a whole. In 1996 the median age of Travellers was 14 years, in comparison to a national figure of 31 years. The weighting of the Traveller population in favour of youth is probably due to

- The fact that life expectancy is significantly lower for Travellers (both male and female) in comparison to the national average and
- The high birth rate among the Traveller population.

In 1987 the general fertility rate for the Traveller community was 164.2 women (per 1000 women, aged 15 - 49) in comparison to 70.1 women (per 1000 women, aged 15 - 49) for the overall population.

# **Life Expectancy**

The most up to date statistical analysis of Travellers' health was commissioned by the Health Research Board and carried out on behalf of the Department of Health by Barry and others in 1986 and 1987. ( *Joseph Barry, Bernadette Herity, Joseph Solan: The Travellers Health Status Study: Vital Statistics of Travelling People* ).

This analysis included statistics on life expectancy which showed that Travellers were only then reaching the life expectancy that settled Irish people reached in the 1940's. The figures showed that:

- Travellers of all ages have much higher mortality rates than people in the general population.
- Traveller women live on average 12 years less than women in the general population.
- Traveller men live on average 10 years less than men in the general population.

As no similar study has been carried out since 1987, it is impossible to determine if Travellers' life expectancy has improved since then. However, since Travellers remain disadvantaged in other areas of health status and access to health services generally, it is reasonable to assume that there has been little, if any, improvement since then

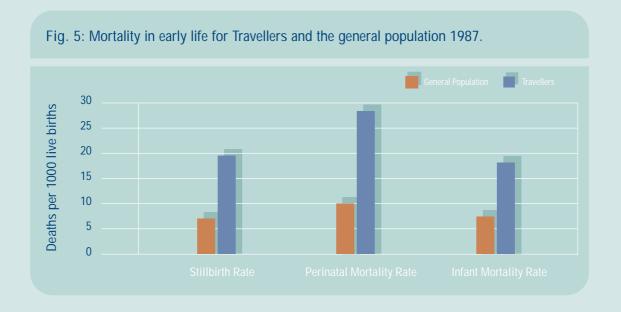


Ref: Vital Statistics of Travelling People 1987

4.9

# **Infant Mortality - Newborn and Infant Deaths.**

The infant mortality rate in 1987 for Travellers was 18.1 per 1000 live births compared to a national figure of 7.4.



#### **Infant Mortality rate:**

Number of deaths of infants in the first year of life per annum per 1,000 live births.

#### Stillbirth rate:

Number of stillbirths (babies weighing 500 grams or over who are born dead) per year divided by the total number of live and stillbirths.

#### Peri-natal mortality rate:

Number of stillbirths and number of liveborn babies who die before the end of the first seven days of life per year divided by total number of live and stillbirths.

Source: Vital Statistics of Travelling People 1987

## Sudden Infant Death Syndrome and Traveller children

The occurrence of Sudden Infant Death Syndrome (SIDS) among Traveller families in 1999 was twelve times the national figure (8.8 Vs. 0.7 per 1000 live births). This figure is based on the rough estimate of the total number of live births amongst Traveller families in 1995. (Information is based on demographics of Traveller children provided by the 1996 Census of Population.) While the absolute number of cases of SIDS among Traveller families each year is small, from 1992 to 1999 the rate of occurrence of SIDS among the Traveller community was higher than the national rate. In 1999 11.4 % of SIDS cases occurred in Traveller families.

Source: Irish Sudden Infant Death Association -National Sudden Infant Death Register – 1999 Report

## **Living Conditions and Travellers' Health**

4.10

Some of the key determinants of health exist outside the formal health care sector. This Strategy includes proposals which will ensure that full account is taken of these factors, in the course of future planning and delivery of health services.

One important area is that of Traveller accommodation and the conditions in which many Travellers live from the perspective of health and safety.

## 4.12

The most recent count of Traveller families for which figures are available (conducted in November 2000) described 1093 families as living on the side of the road. Such families are without even basic facilities and in many cases, are liable to be moved on in accordance with local authority powers. The information in Table 1 indicates that almost one in every four Travellers has no piped water supply ( or at best has a shared cold water supply ), no flush toilet, no bath or shower, no access to mains electricity and no refuse collection.

Table 1: Number of Traveller families by type of accommodation - 1981 and 2000

	1981		2000	
Type of Accommodation	Number	%	Number	%
Standard local authority housing, Group Housing, Private Housing assisted by local authority, housing provided by voluntary bodies with local authority assistance	1,135	46.5	2,653	54.2
Halting Sites ( see also Fig 6 )	174	7.1	1,152	23.5
Total Accommodated	1,309	53.6	3,805	77.7
On the Roadside	1,132	46.4	1,093	22.3
Overall Total	2,441	100	4,898	100

Table 2: Permanent and Temporary Halting Sites - 2000					
Type of Site	Number of Families	%			
Permanent Halting Sites Temporary Halting Sites	833	17.0			
( in place for more than two years )	223	4.5			
Temporary Halting Sites ( in place for less than two years)	84	1.7			
Transient Halting Sites	12	0.2			
Total	1152	23.4			

(Source for both tables: Dept. of the Environment and Local Government)

#### 4.13

In 2000, 407 Traveller families were living in private accommodation which was not assisted by the local authority and 140 Traveller families were sharing accommodation with relatives.

#### 4.14

There is little doubt that the living conditions of Travellers are probably the single greatest influence on health status. Stress, infectious disease including respiratory disease and accidents are all closely related to the Traveller living environment. It is clear that an immediate improvement to the living environment of Travellers is a prerequisite to the general improvement in health status.

#### 4.15

While neither the Department of Health and Children nor the Health Boards have a major direct role or responsibility in relation to the living environment of the Traveller Community (and /or accommodation provisions), it is important that close links be established between the health sector and the environmental authorities and that there should be maximum co-operation in addressing the environmental factors which have such a significant influence on the health status of Travellers.

#### **ACTION PROPOSED:**

Discussions will take place between the Department of Health and Children and the Department of the Environment and Local Government to examine and determine an appropriate liaison arrangement, including representation from Traveller organisations, between the two Departments with a view to addressing issues of common concern relating to Travellers.

The two Departments will be asked to examine issues including the inspection of halting sites, health and safety matters on halting sites and the role of the two Departments, Health Boards and local authorities in addressing these issues and to report within 12 months of the publication of this Strategy.

The 1996 Census is now widely acknowledged to have greatly underestimated the number of Travellers in Ireland at 10,891.



# CHAPTER 5

INFORMATION ON TRAVELLERS' HEALTH

...CURRENT SYSTEMS OF DATA COLLECTION DO NOT IDENTIFY TRAVELLERS AS A PARTICULAR ETHNIC GROUP...

There is currently no systematic or regular gathering of data relating to the health status of Travellers. The major barrier to achieving this is the absence of any specific identifier of Travellers within the existing health data-gathering systems in use in hospitals or the community. The absence of specific data makes it difficult to plan and monitor services for Travellers. The collection of data relating to ethnic origin is, however, both technically and administratively possible.

### 5.2

There has been no significant statistical analysis of Travellers' health since the Barry / HRB study in 1986 / 1987. However, as background information for the 1995 Task Force Report, a study on the uptake of health services was carried out by the Department of Health Promotion Studies (University College Galway) and Patricia McCarthy and Associates, Dublin. The study was conducted by carrying out interviews with 200 Travellers in Dublin and Galway and service providers in all Health Board areas, in order to establish the main issues in relation to Travellers' access to the health services.

#### 5.3

Current systems of data collection do not identify Travellers as a particular ethnic group. However, in preparing this Strategy, regard was had to the recommendations of the Task Force in this respect. The information requirement implicit in the Task Force recommendations is that Travellers should be identifiable and that the full range of health status indicators should be measurable for them.

#### 5.4

The Programme for Prosperity and Fairness (PPF) provides for the development of a system for the collection of data on Travellers under the headings of social inclusion and healthcare. Making significant progress in tackling Traveller health status will be difficult unless an adequate system can be put in place to gather data on an ongoing basis on Traveller health. 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 existing health information systems in order to identify Travellers as an ethnic group.

The Department of Health and Children has commenced discussions with the Economic and Social Research Institute with a view to examining the feasibility of including ethnic identifiers for Travellers and other ethnic groups in the Hospital Inpatient Enquiry (HIPE) and Perinatal Systems. Initially, this should involve the development of pilot projects for one or both of these systems. The experience gained from these projects should then be used to extend Traveller identification to other health information systems.

This would include mortality and other vital statistics databases as well as morbidity information systems such as the National Cancer Registry, school health data and dental health data. It would also extend to data on the General Medical Services (GMS), infectious disease notification, and other health and health service data.

This work will be carried out in participation with the Traveller organisations as represented on a Working Group on Traveller Ethics and Research which is to be established. More broadly, initiatives and actions in the area of improved information on ethnicity should be specifically included in the implementation programme of the National Health Information Strategy (NHIS) which is currently being developed.

#### **ACTION PROPOSED:**

- A pilot project will be initiated during 2002 to collect information on ethnicity (including Travellers and other ethnic groups) from the HIPE and/or Perinatal Systems.
- The results of this pilot will be evaluated with a view to extending identification of ethnicity to other relevant health information systems as part of the implementation programme for the National Health Information Strategy.
- A Traveller Needs Assessment and
  Health Status Study will be carried out
  to develop and extend indicators
  collected in the last survey of
  Travellers Health Status (Barry, 1987)
  and to inform appropriate actions
  required in the area of Travellers'
  health.
- A working group on Traveller Ethics and Research will be established no later than March 2002 by the Department of Health and Children in conjunction with other relevant agencies.

The group will include representation from the Traveller Health Advisory Committee and other appropriate personnel. Its remit will include:

- 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 this Strategy (including the Needs Assessment referred to above).

Making significant progress in tackling Traveller health status will be difficult unless an adequate system can be put in place to gather data on an ongoing basis on Traveller health. 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.



# CHAPTER 6

ORGANISATION AND MANAGEMENT

THIS STRATEGY CALLS FOR SIGNIFICANT CHANGES IN ATTITUDE, APPROACHES AND ACTIONS TOWARDS TRAVELLERS THROUGHOUT THE HEALTH SERVICES.

This Strategy calls for significant changes in attitude, approaches and actions towards Travellers throughout the health services. Implementation of these changes will require specific funding, staffing and management supports to be strengthened at national, regional and local level.

## 6.2

## The Department of Health and Children

At national level, the Department of Health and Children has a role to play in devising overall policy in relation to Travellers' health and monitoring its implementation. Ensuring the success of this Strategy will require close liaison with various other Government departments whose areas of responsibility impinge on Travellers' health, as well as ongoing contact with the various health agencies and other relevant stakeholders. The additional workload will have implications for the organisation and staffing of the Department in relation to Travellers' health.

#### 6.3

# Traveller Health Policy Unit, Department of Health and Children.

The Traveller Health Policy Unit within the Department of Health and Children will:

- support the Traveller Health Advisory Committee
- plan and monitor the allocation of national and regional funding for Travellers' health (including new service initiatives).
- be responsible for monitoring the health status of Travellers and their access to services

- co-ordinate and liaise with other Government Departments in respect of issues relevant to Travellers' health.
- oversee the implementation of the National Traveller Health Strategy and report annually on progress.

# The Traveller Health Advisory Committee

The work of the Traveller Health Advisory Committee (THAC) has been crucial to the preparation of this Strategy. In addition to this important work, the Committee's brief also includes the following:

- Ensuring that Traveller health is a priority area within the Department of Health and Children and setting targets by which performance can be measured
- Ensuring co-ordination and liaison in the implementation of national strategies of relevance to the health status of Travellers
- Ensuring the co ordination, collection and collation of data on Travellers' health
- Supporting Health Boards in developing strategies to improve Travellers' access to health services
- Providing a forum for the discussion of health initiatives for Travellers and for ongoing consultation with Travellers and Traveller organisations for the delivery of health services to Travellers
- Liaising with Traveller Health Units in health boards in the formulation of national policy

## **Traveller Health Units**

The Report of the Task Force on the Travelling Community recommended that each Health Board establish a Traveller Health Unit with the following functions:

- Monitoring the delivery of health services to Travellers and setting regional targets against which performance can be measured.
- Ensuring that Travellers' health is given prominence on the agenda of the Health Board.
- Ensuring co-ordination and liaison between the Health Boards, and between the Health Board and other statutory and voluntary bodies, in relation to the health situation of Travellers.
- Collection of data on Travellers' health and utilisation of health services.
- Ensuring appropriate training of health service providers in terms of their understanding of and relationship with Travellers.
- Supporting the development of Traveller specific services either directly by the Health Board, or indirectly through funding appropriate voluntary organisations.

#### 6.6

A number of Health Boards have implemented the recommendation of the Task Force in relation to Traveller Health Units and they are now fully functional and working in partnership with local Traveller organisations. Others have reportedly established Traveller Health Units without consultation with local Traveller organisations. A significant function of each Unit should be to build the capacity of Travellers to participate effectively in service initiatives.

Traveller representatives on some committees feel that they are operating without support or the resources which are necessary to ensure they can be properly briefed on the issues for discussion. Others find it difficult to participate in the absence of recompense for the cost of travel or childcare.

## Management of Travellers' Health

#### 6.8

It is important that each Health Board should have a Senior Manager with responsibility for Travellers' health. Each Board should provide the support and resources to ensure that the health needs of the Traveller population in its area are addressed.

## 6.9

At present, the Traveller Health Units differ in their format from one Board to another. Depending on the particular model adopted in any Health Board area, it is considered important that these units should have a role in the following:

- The development of service plans.
- Planning and monitoring research into Travellers' health status and access to health services in conjunction with other boards and the THAC.
- Production of information for inclusion in the Health Board's Annual Report.
- Liaison with Managers for Travellers' Health in other Health Board areas.
- Liaison with Local Traveller Accommodation Consultative Committees in the relevant local authorities

#### 6.10

It is also important to note that all service providers have a responsibility towards Travellers and it should not be the sole prerogative or responsibility of those in the Traveller Health Unit or other designated personnel.

#### **ACTION PROPOSED:**

- The Department of Health and
  Children will continue to draw on the
  ongoing advice of the Traveller Health
  Advisory Committee in the course of
  the implementation of this Strategy
  and in the development of new
  initiatives
- An immediate review and survey of the state of implementation of Traveller Health Units and the models developed in each Health Board area will be carried out by the Traveller Health Policy Unit at the Department of Health and Children, in consultation with the Traveller Health Advisory Committee (THAC).
- In addition to the functions listed earlier, each Traveller Health Unit will be required to draw up a regional action plan for the implementation of the proposals in this Strategy within six months of its publication.
- Specific funding will be allocated to enable Traveller Health Units to implement this Strategy and to progress new health initiatives, in accordance with agreed action plans

- Funding will be allocated to Traveller Health Units to be used to resource Traveller groups to participate effectively in the units. For example the funding may be used to employ a Community Worker, engage in capacity building, health training or primary health care training and provide transport and childcare allowances.
- Traveller Health Units will furnish annual reports (including financial information) on progress in the implementation of regional action plans.
- Appropriate information will be provided to Traveller organisations on the general health status of Travellers, their uptake of services, and other factors impacting on Travellers' health
- Training on Traveller culture and issues of racism and discrimination will be provided for members of the Traveller Health Unit, in partnership with Traveller organisations.
- A senior manager will have responsibility in each Health Board area, as outlined at 6.8.
- Health Board service plans should be subject to "Traveller proofing" and a template which is currently being piloted in the Eastern region may be of assistance in this regard.

A number of health boards have implemented the recommendation of the Task Force in relation to Traveller Health Units and they are now fully functional and working in partnership with local Traveller organisations. Others have reportedly established Traveller Health Units without consultation with local Traveller organisations. A significant function of each unit should be to build the capacity of Travellers to participate effectively in service initiatives.



# CHAPTER 7

HEALTH PROMOTION

...HEALTH PROMOTION... RECOGNISES
THAT INDIVIDUALS WISHING TO ADOPT
A HEALTHY LIFESTYLE MAY BE
PREVENTED FROM DOING SO BY
ENVIRONMENTAL AND SOCIO-ECONOMIC
FACTORS, WHICH ARE OFTEN BEYOND
THEIR INDIVIDUAL CONTROL...

Health promotion is a concept that is broader than disease prevention and health education. It recognises that individuals wishing to adopt a healthy lifestyle may be prevented from doing so by environmental and socio-economic factors, which are often beyond their individual control. Health promotion at an individual level involves educational processes enabling people to acquire information and skills that will help them to make good decisions in relation to their health. At a community, regional and national level it involves the development of appropriate policies, structures and support systems so that the healthier choice is an easier choice. For Travellers in particular, the lack of culturally appropriate education and training materials has contributed to the low uptake and utilisation of preventative action and curative services.

#### 7.2

In recognition of the fundamental importance of health promotion, a number of health education and health promotion initiatives have been pursued in recent years, specifically focusing on Travellers' health. Experience has shown that the success of these initiatives is closely related to the extent of the involvement of Traveller organisations in the drafting, design and dissemination of the material used. Video and posters have been shown to be the most effective media for conveying important health messages to the Traveller community.

#### 7.3

As indicated in Chapter 4, it is now widely acknowledged that many of the major determinants of health such as social, environmental and economic factors are beyond the direct remit of the health sector. The Health Promotion Strategy 2000-2005 acknowledges this and calls for the development of intersectoral collaboration through the establishment of a National Health Promotion Forum. The new Forum will be widely representative and its membership will include representatives of those Departments and agencies whose policies/actions have a direct or indirect impact on health determinants. If the inequalities which exist in Travellers' health, particularly those relating to income, education, discrimination and accommodation, are to be addressed at a macro level, it is imperative that Travellers and Traveller organisations are included in the membership of the Forum.

The lack of current information on the health status of Travellers and the difficulty of planning effective interventions arising from this, have been referred to in Chapter 5. Accordingly, the outcome of research gathered during the proposed Traveller Needs Assessment and Health Status Study (page 34) can be expected to influence strongly the development of culturally appropriate health promotion programmes for Travellers.

# **Regional / Community Level**

## 7.5

The Health Promotion Strategy 2000-2005 sets out a number of strategic aims and objectives. However, the Health Promotion Unit of the Department of Health and Children is continuing to devolve its executive and operational functions to the Health Boards and consequently the boards have autonomy in planning, developing and implementing health promotion interventions at a regional and community level. However there is a need to ensure that all health promotion programmes are Traveller proofed.

## **ACTION PROPOSED:**

- Health Boards will ensure that health promotion programmes are culturally sensitive and appropriate and recognise the particular constraints under which many Travellers live. The most effective means of ensuring this is to allocate Traveller organisations a central role in both the design and delivery of services. (For example: the methodology used and the content of health promotion material should take account of literacy levels ensuring clarity and ensuring that such material is culturally appropriate. Materials such as posters and videos should be chosen rather than leaflets.)
- The Health Promotion Unit, the
  Traveller Health Policy Unit, and the
  Traveller Health Advisory Committee
  will work with Traveller and other
  relevant organisations on initiatives to
  inform the settled community of the
  detrimental impact which living
  circumstances and ongoing
  discrimination have on Travellers'
  health
- Travellers' health should form part of the agenda of the National Health Promotion Forum and Traveller representatives will be invited to join the Forum.

- As outlined in Chapter 5, a Traveller Needs Assessment and Health Status study will be commissioned and carried out as a matter of urgency. The results of this research will inform and influence the provision of health promotion programmes as they apply to Travellers.
- The National Health Promotion Forum should encourage health - proofing of any public policy relevant to Travellers' health.
- Traveller Health Units, in partnership with regional Health Promotion Units will identify and prioritise existing mainstream health promotion programmes and initiatives which should be Traveller proofed.
- The priority areas identified as a result of this action should be adapted as appropriate to ensure that they are Traveller proofed.

11 In recognition of the fundamental importance of health promotion, a number of health education and health promotion initiatives have been pursued in recent years, specifically focusing on Travellers' health. Experience has shown that the success of these initiatives is closely related to the extent of the involvement of Traveller organisations in the drafting, design and dissemination of the material used. Video and posters have been shown to be the most effective media for conveying important health messages to the Traveller community."



MEN, WOMEN AND CHILDREN

...THE HRB REPORT INDICATES THAT THE INFANT MORTALITY RATE IN 1987 FOR TRAVELLERS WAS 18.1 PER 1000 LIVE BIRTHS COMPARED TO A NATIONAL FIGURE OF 7.4 PER 1,000 LIVE BIRTHS....

It is anticipated that specific health programmes targeted at Traveller men, women and children will emerge during the course of this Strategy, following the analysis of research evidence. In the meantime, a number of initiatives can be taken on the basis of what is known at present.

# 8.2

Information from the Barry / HRB report indicates that the infant mortality rate in 1987 for Travellers was 18.1 per 1000 live births compared to a national figure of 7.4. If mortality rates are to be reduced among Travellers, particular attention must be given to what happens to Traveller women of childbearing age and also to the appropriate delivery of child health services for Travellers. While the Health Promotion proposals outlined earlier will aim to increase awareness and appreciation of the value of various health services, much more needs to be done to ensure greater utilisation of the relevant services. Evidence from the UCG/McCarthy report shows a pattern of low utilisation of preventive and after-care services including ante-natal and post-natal services, paediatric services and immunisation.

# **Maternity Services**

# 8.3

Given their relatively high fertility rate (Barry / HRB 1986/87), it is not surprising that Traveller women have a higher utilisation rate of obstetric services. However, this is accompanied by a lower uptake of other maternity services. Among the problems which the UCG / McCarthy report identified was a poor understanding of the value of ante-natal and post-natal care among Travellers. There was a low up-take of ante-natal classes and a low up-take of ante-natal and post-natal check-ups. Other areas of concern include a low uptake of family planning services and a low rate of breast feeding.

The report also identified a low uptake of child health services including immunisation, where for example there was an immunisation rate of 52% for MMR as against a national uptake of 75%. There was also a poor uptake of developmental paediatric services and specialist child health services. The present appropriateness of these services and the ways in which they are delivered to Travellers are called into question by these low utilisation rates.

The report also identified a low uptake of child health services including immunisation, where for example there was an immunisation rate of 52% for MMR as against a national uptake of 75%. There was also a poor uptake of developmental paediatric services and specialist child health services. The present appropriateness of these services and the ways in which they are delivered to Travellers are called into question by these low utilisation rates.

The specific action proposed under the heading of Health Promotion, and Public Health Nursing initiatives proposed later in Chapter 11, will impact on the quality and uptake of women's health services. The following will be implemented in relation to maternity services in particular:

- Health education programmes for Travellers will highlight the relevance of proper ante-natal and post-natal care. Consideration will be given to providing culturally appropriate antenatal education and care for first time Traveller mothers. Where possible, consideration will be given to providing decentralised ante natal clinics throughout the country.
- The Maternity and Infant Care Scheme (shared care/GPs and maternity hospitals) will be promoted to encourage earlier ante natal registration. Health promotion material for expectant mothers will be culturally appropriate. Care will be planned jointly with each expectant mother according to her individual needs and wishes commencing in 2002
- Liaison between maternity units and the Designated Public Health Nurses (see Chapter 11) will be improved to ensure early identification of Traveller mothers, prompt birth notification, more timely communication regarding discharge dates of mother and baby

- and better follow up. This will commence within six months of publication of this Strategy.
- The need for special tests such as the Guthrie test and Butchler test will be adequately explained to Traveller mothers in the ante natal period. Mothers will be supported and encouraged to stay for an appropriate period of time in hospital following birth so that the full range of post natal services are availed of.
- From the desired provided of the latter access to and uptake of family planning and sexual health services will be encouraged by Health Boards through improved primary care services. Where appropriate, special Health Board clinics should be held at which the necessary services can be provided.
- Peer led educational and awareness programmes on family planning and sexual health should be considered by Health Boards, as should other means of communication such as videos, which may be more appropriate to Travellers' needs than written materials
- The opportunity should be taken, in the context of Travellers availing of post - natal services, to discuss women's future contraceptive needs.

# **Violence against Traveller Women**

#### 8.5

While the situation for all women who have to leave their home in search of a violence-free life is difficult, Traveller women experience additional dilemmas which make it more difficult for them to access help and support and explore their options. This is brought about by a combination of discrimination in services and professions (institutional and individual) and a lack of culturally appropriate provision.

#### 8.6

Pavee Point, a voluntary organisation which campaigns for human rights for Travellers, has described the following issues which face Traveller women experiencing male violence:

- All Travellers have difficulty accessing mainstream services for a variety of reasons. This institutional discrimination exacerbates the situation for a Traveller woman attempting to access GPs, Accident and Emergency services, crisis services, refuges and related support services.
- Due to preliteracy or illiteracy, Traveller women experience difficulties in accessing information and legal options.
- The often conflictual relationship between the Gardai and the Traveller community makes it very difficult for Traveller women to access help from the Gardai. This has a direct effect on women's use of the judicial system. Women often find themselves having to make the choice between seeking protection for themselves and protecting their community from external criticism.

- Access to women's refuges in each Health Board area should be monitored to ensure that no barriers exist for Travellers and that they are inclusive of Travellers' needs.

  Attitudes and behaviour towards domestic violence should be a key part of focused health promotion programmes.
- Travellers and Traveller organisations will be represented on all national and regional steering groups addressing the issue of violence against women.
- Any research projects undertaken on the issue of violence against women will include a Traveller dimension following approval by the Traveller Ethics and Research Working Group.

- Traveller organisations promoting special initiatives addressing the issue of violence against women will be supported.
- Refuges will be encouraged to develop and adopt anti racist codes of practice and to provide in service training in anti racism and interculturalism.
- Initiatives to work with Traveller mer perpetrating violence will be supported.
- Traveller organisations will be funded to train and employ Traveller women as refuge workers and counsellors.

# Traveller Men's Health

#### 8.7

The 1995 Task Force Report noted that male Travellers have over twice the risk of dying in a given year than settled males. There may be particular challenges associated with the planning and successful delivery of appropriate services for Traveller men, as experience has shown that Traveller men tend to show some reluctance in becoming involved in health care initiatives.

## **ACTION PROPOSED:**

The Traveller Needs Assessment and Health Status Study, proposed in Chapter 5, will include specific references to the health needs of Traveller men. The findings of the study will inform the provision of culturally appropriate initiatives on Traveller men's health.

"The 1995 Task Force Report noted that male Travellers have over twice the risk of dying in a given year than settled males."



PRIMARY HEALTH CARE

THE INHERENT APPROACH IS TO WORK 'WITH' THE TRAVELLER COMMUNITY IN ORDER TO DEVELOP A PRIMARY HEALTH CARE PROJECT BASED ON THE TRAVELLER COMMUNITY'S OWN VALUES AND PERCEPTIONS SO THAT POSITIVE OUTCOMES CAN HAVE A LONG-TERM EFFECT.

The concept of Primary Health Care was established at the joint WHO / UNICEF conference in Alma Ata in 1978.

## 9.2

The WHO Alma Ata declaration described primary health care as:

"ESSENTIAL HEALTH CARE BASED ON PRACTICAL, SCIENTIFICALLY SOUND AND SOCIALLY ACCEPTABLE METHODS AND TECHNOLOGY MADE UNIVERSALLY ACCESSIBLE TO INDIVIDUALS AND FAMILIES IN THE COMMUNITY THROUGH THEIR FULL PARTICIPATION, AND AT A COST THAT THE COMMUNITY AND COUNTRY CAN AFFORD TO MAINTAIN AT EVERY STAGE OF DEVELOPMENT IN THE SPIRIT OF SELF - RELIANCE AND SELF - DETERMINATION. IT FORMS AN INTEGRAL PART BOTH OF THE COUNTRY'S HEALTH SYSTEM, OF WHICH IT IS THE CENTRAL FUNCTION AND MAIN FOCUS, AND OF THE OVERALL SOCIAL AND ECONOMIC DEVELOPMENT OF THE COMMUNITY. IT IS THE FIRST LEVEL CONTACT OF INDIVIDUALS, THE FAMILY AND THE COMMUNITY WITH THE NATIONAL HEALTH SYSTEM, BRINGING HEALTH CARE AS CLOSE AS POSSIBLE TO WHERE PEOPLE WORK AND LIVE".

Primary Health Care has been identified and used as an innovative approach to health care in the developing world. In the last decade there has been a growing interest and demand for such a service in the developed world as evidence from studies indicates that marginalised populations are suffering disproportionately from poor health and have less access to health care services.

#### 9.3

Primary Health Care in communities means enabling individuals and organisations to improve health through informed health care, self help and mutual aid. It means encouraging and supporting local initiatives for health. Successful primary health care projects have emphasised a process that values empowerment, partnership and advocacy when designing and implementing health care interventions. This allows the partners to

highlight inequity and negotiate mutually acceptable solutions. Community participation and intersectoral collaboration are key requisites for the success of Primary Health Care. The inherent approach is to work 'with' the Traveller community in order to develop a Primary Health Care project based on the Traveller community's own values and perceptions so that positive outcomes can have a long - term effect.

## 9.4

In Ireland, the first Primary Health Care for Travellers Project was established in Dublin as a joint partnership initiative between the (then) Eastern Health Board and Pavee Point. The project began as a pilot initiative in October 1994 in the Finglas/Dunsink areas of Community Care Area 6, with funding from the Eastern Health Board.

A notable feature of this project has been the recruitment and training of Community Health Workers ( CHWs ) drawn from the Traveller community itself.

# 9.5

A number of similar projects have been up and running for some time and are credited with bringing real and substantial benefits to the Traveller communities where they are located. Working with public health nurses, dentists, dental nurses, and other health professionals, the CHWs have been responsible for remarkable improvements in levels of access to child health services including immunisation, women's health services, family planning and oral / dental health services. In view of these successes over such a range of services, the extension and further development of similar projects is proposed as a cornerstone of this Strategy.

# 9.6

In the original pilot project, a partnership model of working between Pavee Point and the Eastern Health Board was reflected particularly in the co-ordination and management structure of the project. A relevant health professional (at the time a public health nurse) was assigned to the project by the Eastern Health Board, and a community worker by Pavee Point. The range of skills and expertise which the co-ordinators brought to the project contributed to its success. A balance in approach between health and community development was reflected in the staff backgrounds and is particularly appropriate in the development of a Primary Health Care approach to health issues. The co-ordinators were jointly responsible for the co-ordination and delivery of the project on a day to day basis and they were responsible for convening and resourcing steering group meetings.

The project included a training course which concentrated on skills development, capacity building and empowerment of Travellers. This confidence and skill allowed the CHWs to go out and conduct a baseline survey to identify and articulate Travellers' health needs. This was the first time that Travellers were involved in this process. In the past, their needs had been assumed. The results of the survey were fed back to the community and they prioritised their needs and suggested changes to the health services which would facilitate their access and utilisation. The results were also fed back to the health service providers, following which a joint workshop took place between the Traveller community and the health providers where an agreed set of priorities and interventions was drawn up. The health workers then set about implementing these interventions. This was a very effective process as it facilitated the participation of the community in defining needs, setting priorities and outlining interventions and it provided baseline data on the current access and use of services.

This process has been critical to the success of the project as people are engaging and are confident to articulate their needs. One of the findings of the baseline survey was the lack of appropriate health information on what services existed and how, where, and why these services should be accessed. This has been addressed in the project and has led to an increased uptake of the health services.

# Outcomes of the project

# 9.8

Greater awareness has been created about the needs, entitlements and possibilities in the health services as well as the difficulties in accessing such services.

# 9.9

Sixteen Traveller women have received accredited training as Community Health Workers and are currently employed on the project, funded by the (former) Eastern Health Board and now by the three area Health Boards in the ERHA region.

The process of facilitating community participation in the project has resulted in the empowerment of Travellers and led to their taking more control of their health situation. Their attitudes to the health system have changed through the provision of information, training and resources. This in turn has brought about a change in their ability to access the system. They are making greater demands on health services and have greater expectations for the health services to be provided in culturally appropriate ways.

#### 9.11

The project has also impacted on the wider Traveller community via Traveller organisations throughout Ireland, with a growing realisation of the potential of health initiatives among the Traveller community.

# 9.12

The ongoing monitoring and data collected to date demonstrates a big improvement in the levels of satisfaction, uptake and utilisation of health services by Travellers in the area. Based on this experience, this Strategy recognises the value of community participation in the planning and delivery of primary health services and the further potential of Primary Health Care for Travellers Projects.

The initiative described above is successfully being replicated in many other areas. It is imperative that the replication strategy is supported to facilitate the development of these projects and maintain standards in CHW training.

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- Primary Health Care for Travellers
  Projects will be developed in
  conjunction with Traveller
  organisations in all Health Board
  areas where there is a significant
  Traveller population by the end of
  2005. The Department of Health and
  Children will provide funding to allow
  for the freeing up of staff and other
  resources on the part of appropriate
  organisations in order to implement a
  suitable strategy for replication of the
  Projects in relevant areas.
- Each Primary Health Care for Travellers Project will have two Coordinators, a relevant health professional, employed by the Health Board and a Community Health Worker, employed by the Traveller organisation.
- In developing the Primary Health Care for Travellers Projects there will be an

- emphasis on flexibility and innovation in order to respond to differing circumstances and differing health needs as identified by Travellers in each area
- The projects will be periodically evaluated and progress reports made available to the Traveller Health Advisory Committee at the Department of Health and Children.
- As they are developed, the Projects will be used as a resource to train Health Board staff and other health professionals in anti-racism skills, Traveller culture and good practice in addressing Traveller health needs.
- Commencing in 2002, the Department of Health and Children will support an annual conference to share experience and learning of Primary Health Care for Travellers Projects

# Patient and Family Held Records

# 9.13

In the U.K., a system of patient held records for use by Traveller families has been piloted and has proved to be effective. It would be desirable to introduce such a system for Irish Traveller families. A pilot project should be initiated to identify how a patient and family held record system would work for the Traveller community. Such records may contain information on a patient's medical history, all general practice and hospital consultations, obstetric history and details of prescribed medicines. The use by Travellers of such a system would, of course, be voluntary.

Progress on this project would be monitored by the Department of Health and Children in consultation with the Traveller Health Advisory Committee, with the aim of introducing a durable and user-friendly patient and family held record for use by all Health Boards.

#### 9.15

Agreement would also need to be reached on a set of symbols / colour codes to be used nation - wide to facilitate easy understanding of instructions on the use of medications. Symbols designed for use by adults with literacy difficulties could be produced on an adhesive label format for GPs, hospital doctors and nurses and pharmacists. Ideally, these should be ready for introduction at the same time as the patient held record.

## **ACTION PROPOSED:**

- The Department of Health and Children will establish a Working Group comprised of Traveller organisations, members of the Traveller Health Advisory Committee, the Irish College of General Practitioners, and Public Health Nurses working with Travellers. The group will draft the content and agree the design of a durable and user friendly patient and family held record to be used by all Health Boards.
- The group will be convened within three months of publication of this Strategy and report to the Department with its recommendations after a further six months. Introduction of the new record on a nationwide basis should commence not later than June 2003



GENERAL PRACTITIONER SERVICES

...THE UCG/MC CARTHY REPORT STATED THAT 17% OF THE TRAVELLERS INTERVIEWED HAD EXPERIENCED DIFFICULTY IN REGISTERING WITH A GENERAL PRACTITIONER (GP). IN MANY AREAS, IT WAS FOUND THAT ONLY A SMALL NUMBER OF GPS PROVIDED SERVICES TO TRAVELLERS...

The UCG/McCarthy report stated that 17% of the Travellers interviewed had experienced difficulty in registering with a general practitioner (GP). In many areas, it was found that only a small number of GPs provided services to Travellers. The study also found that having a relationship mainly tied to one specific doctor does not suit the nomadic lifestyle of Travellers.

# 10.2

In relation to house calls, the report stated that GPs are generally reluctant to go out on call to halting sites, particularly unofficial sites. This is partly explained by the general move away from domiciliary visits especially at night. There may also be fears regarding personal safety among GPs.

# 10.3

Other difficulties outlined in the report included the fact that Travellers attending surgeries tend to be accompanied by large numbers of family members which GPs regard as disruptive. Reference was also made to the fact that often members of the settled community will not wait in a waiting room with Travellers. This type of prejudice ensures that doctors can be reluctant to treat Traveller patients.

#### 10.4

There are various factors which impede the achievement of a high level of quality of care. For example, continuity of care can be a serious issue with many Traveller families seeing a series of different GPs in the course of a year. Many Traveller men rarely attend the GP, sending their wives instead to renew prescriptions. From the Travellers' point of view there can be complaints that consultations are too hurried, with little time being taken to give the reason for a prescription or to explain a diagnosis or how to manage a problem but there is no evidence to indicate that the latter situation, if it does exist, is related only to Travellers.

It is fully recognised that general practice does not exist in isolation from other areas of healthcare provision and the contribution that general practice can play in meeting and enhancing the overall healthcare of Travellers is significantly dependent on the development of an integrated strategy beginning with health promotion and encompassing all health sectors in an integrated fashion. Accordingly, the Department of Health and Children and the Health Boards will seek to develop the appropriate linkages between general practitioners and public health nurses, health promotion officers, community health workers, and other primary and secondary care providers. However, the time required for the development of those linkages should not serve to prevent the implementation of the actions identified below, which are themselves consistent with a strategic approach.

# 10.6

Following their recent review of the operation of the medical card scheme, the CEOs of the Health Boards have recommended that each Health Board should have in place special arrangements to cater for the needs of at risk groups including Travellers, in a culturally appropriate manner, and that the adoption generally by all Health Boards of some of the existing models in place to cater for such groups would go a long way to effect improvements for everyone concerned.

The CEOs of the Health Boards have recommended that each Health Board should have in place special arrangements to cater for the needs of at risk groups including Travellers in a culturally appropriate manner, and that the adoption generally by all Health Boards of some of the existing models in place to cater for such groups would go a long way to effect improvements for everyone concerned.

- Health Boards and the ERHA, in liaison with Traveller representative organisations, will monitor access by Travellers to general practitioner services on a regular basis and will report annually on developments and progress in this regard.
- In line with the provisions of the Equality Act, in any future review of the General Medical Services (GMS) Scheme contract, the terms of the contract will be expressed so as to limit the circumstances in which a general practitioner who is a contracted GMS Scheme doctor can refuse to register a Traveller patient.
- The Department of Health and Children, the ERHA and the Health Boards will ensure that the criteria used in determining future funding support for GMS projects generally take account of the needs of Travellers and have regard to the extent to which any service improvement benefits Travellers.
- The development of existing 'GP out of Hours' projects being piloted should have equal regard to Travellers' needs.
- Health Boards' Primary Care Units should be represented on Traveller Health Units in each area. Such representation will facilitate greater liaison between the Primary Care Unit

- and the Traveller Health Unit with regard to General Practice issues relevant to Travellers.
- The Primary Care Unit manager should be a member of the Traveller Health Unit. Such membership will allow the manager to advise the Traveller Health Unit of developments in general practice that are relevant to Travellers and to be advised by the unit of matters in general practice that are of concern to Travellers.
- To ensure that Travellers benefit from the future potential of information technology in general practice, an appropriately focused pilot scheme will be designed and introduced, as soon as practicable. This will involve the identification of Travellers in the context of their ethnicity.
- The future development of general practice is to be quality based. Accordingly, it is essential that the criteria to be used in establishing quality measures should have regard to the needs of Travellers if the quality concept is to be truly inclusive.
- Health Boards will be encouraged to put special arrangements in place in relation to medical cards for Travellers, as described at 10.6 above.

- The Department of Health and Children will work with the Irish College of General Practitioners ( ICGP ), the University Departments of General Practice, and Traveller organisations in promoting any educational, training or promotional programmes designed by them to highlight issues of Travellers' health at undergraduate, postgraduate, vocational or continuing medical educational levels. As a first step, additional study leave will be granted to any general practitioner wishing to take part in the ICGP's training module in Traveller Culture and Health Needs.
- A health education module will be developed and implemented in partnership with Traveller organisations to increase Travellers' awareness of the range of services that are, at present, available in general practice and of the desirability of availing of these services when required. This module will need to take into account any existing barriers to meaningful access and utilisation of service.

- Applications for research or education on matters of Travellers' health status or needs will be facilitated under the GMS Research and Education Fund. It should have regard to the code of practice on research which is to be prepared by the Working Group on Traveller Ethics and Research proposed in Chapter 5.
- A Primary Care Review of the prescribing processes and practices for the Traveller community will be carried out. (This review will be completed within 12 months of publication of this document.)



PUBLIC HEALTH NURSES

IN THE FRONT LINE OF HEALTH SERVICES PUBLIC HEALTH NURSES PROVIDE A CRITICAL POINT OF CONTACT WITH TRAVELLERS...

In the front line of health services, public health nurses provide a critical point of contact with Travellers. As proposed in Chapter 9, Traveller Community Health Workers will take on a front - line role, according as the Primary Health Care Projects are developed for Travellers. In the short to medium term, however, the role of the Public Health Nurse (PHN) will remain critical to the delivery of a range of services. Up to now, this role in the improvement of Travellers' health has not been adequately defined.

## 11.2

The following issues relating to the public health nursing service were identified by the UCG / McCarthy study:

- Overall, a low level of public health nursing intervention was reported (despite the poor health status of the Traveller population).
- There was a reluctance on the part of Travellers to visit the PHN at the clinic because of hostility from other clients, inadequate waiting facilities for small children, low literacy levels (making form filling difficult) and lack of transport.
- Low uptake of child health services including immunisation, developmental paediatric services and specialist child health services.
- Difficulty in contacting Traveller families to ensure delivery of services.
- Concentration on child health at the expense of other areas.

The level of PHN intervention with Travellers has improved in the six years since the UCG / McCarthy study. A number of Health Boards have newly designated PHNs who deal with Travellers' health issues. While no formal evaluation has been carried out, these initiatives, together with the Primary Health Care Projects, have been described as models of good practice and appear to be linked to improvements in immunisation rates, women's health screening and continuity of care. It is therefore, considered highly desirable that this model of provision should be developed more widely and that the role of the designated PHN should include the following:

- Direct service provision to Travellers of all ages and both sexes including Primary Health Care interventions such as advice, nursing diagnosis and referral.
- Ensuring that individuals understand and are properly utilising medications and special diets prescribed by their GP or by hospital doctors.
- Monitoring the health and social needs of Travellers under their care including gathering data for health surveillance.
- Delivery of health promotion/prevention services, in partnership with the Community Health Worker.
- Co-ordinating/organising appointments with specialist services and follow up.
- Liaison with other relevant personnel including Health Board and local authority social workers, home helps, teachers etc.

#### 11.4

As a guideline, it is envisaged that each full time designated PHN should have a caseload of no more than 150 Traveller families. This figure should be set in each area having regard to levels of dependency, living environment and geographical dispersal. Where PHNs are working only part - time with Travellers, their overall caseload should reflect the necessity to provide a proper service to all their clients, having due regard to the special requirements of Traveller patients.

- Health Boards will be encouraged to appoint designated Public Health Nurses to work with Travellers in accordance with the guidelines outlined above.
- Public health nurses recruited or designated to work with Travellers must have an interest in the area, be experienced and be provided with adequate training in Traveller culture, community development skills, antiracist skills and in health issues specific to Travellers.
- In instances where Travellers have difficulty in accessing postal services, they will have the option of nominating their designated PHN, Community Health Worker or their local Traveller organisation to be sent copies of correspondence relating to appointments (within the bounds of patient confidentiality) between secondary care and specialist services and Traveller families under their care.

The following issues relating to the public health nursing service were identified by the UCG/Mc Carthy study:

Overall, a low level of public health nursing intervention was reported (despite the poor health status of the Traveller population).

There was a reluctance on the part of Travellers to visit the PHN at the clinic because of hostility from other clients, inadequate waiting facilities for small children, low literacy levels (making form filling difficult) and lack of transport.

Low uptake of child health services including immunisation, developmental paediatric services and specialist child health services.

Difficulty in contacting Traveller families to ensure delivery of services.

Concentration on child health at the expense of other areas **II** 



**DENTAL SERVICES** 

UNDER THE DENTAL TREATMENT SERVICES SCHEME, ADULT MEDICAL CARD HOLDERS MAY NOW ATTEND A PRIVATE DENTIST FOR BASIC DENTAL CARE. HEALTH BOARD DENTAL SERVICES WILL GIVE PRIORITY TO PROVIDING DENTAL SERVICES TO SPECIAL NEEDS GROUPS SUCH AS TRAVELLERS.

Under the Dental Treatment Services Scheme, adult medical card holders may now attend a private dentist for basic dental care. Health Board dental services will give priority to providing dental services to special needs groups such as Travellers. Free access by Travellers to private dentists is a relatively new provision and it is too early to say what effect it will have on attendance.

# 12.2

There are a small number of special initiatives in place in relation to services specifically focused on Travellers. These include special Traveller Clinics, which are held in the normal clinic location at health centres etc. and are special by virtue of their specially designated time and the emphasis placed on treating the whole family rather than in relation to any special services that they may provide. Special Traveller clinics will continue in Health Boards with services provided by special needs dental teams.

#### 12.3

In addition to the special services described above, a number of oral health promotion initiatives have been carried out. These include the provision of oral health promotion posters for Travellers in the Eastern Regional Health Authority area and an initiative whereby Traveller Community Health Workers have been working with Oral Health Care Promoters to improve awareness and understanding of dental/oral health issues and access to services.

#### 12.4

A study of the effectiveness of targeted oral health promotion in North Dublin found that the use of posters with culturally appropriate images and messages was effective in increasing understanding and awareness of oral health issues. The same study indicated an important role for Traveller Community Health Workers in oral health promotion and in improving access to services. Of particular significance was the part they played in the operation of a patient reminder system.

- Travellers will continue to be designated as a Special Needs Group in relation to dental services
- Access to dental services will be improved through more widespread provision of special services and through increasing the acceptability to Travellers of mainstream services
- While maintaining the right of any
  Traveller to access mainstream services
  under the Dental Treatment Services
  Scheme, special clinics, with an
  emphasis on care for the whole family,
  will be designated and promoted in areas
  where there is a significant Traveller
  population. These clinics should be
  operational by the end of 2002.
- Special clinics will be timed to cater for particular needs in specific areas. Giver the family focus in these clinics, the opportunity should be used by the Oral Health Care Promoter to hold parallel sessions for mothers of young children.
- A dental register and recall system will be set up in each community care area to be operated jointly by the designated special needs dental team in conjunction with Traveller Community Health Workers / Designated Public
- A dental nurse from each special clinic will be designated as a liaison person in respect of Travellers. His / her role will include liaison with Designated Public Health Nurses and /or with Traveller Community Health Workers on the appointment reminder system and the

- operation of the dental register and recall system.
- On-site screening will be extended as more special clinics are set up. Traveller children who are not accessing the school dental service will be identified and arrangements made through the Traveller Community Health Workers from the Primary Health Care for Traveller Projects to encourage follow up and screening.
- In addition to oral health promotion initiatives developed and co-ordinated at national level, each Health Board, through the Oral Health Promoter and the Primary Health Care Projects will develop programmes and materials suitable for local use.
- The promotion of oral health will be a core objective of Primary Health Care for Travellers Projects. Traveller Community Health Workers working with designated Oral Health Promoters in each area will be responsible for coordinating oral health promotion initiatives including improving access to special and mainstream services.
- population accessing oral / dental health, level of access to services and, if possible, the extent to which fluoride intake is adequate or not, will be undertaken before the end of 2002 and repeated every 10 years. For this survey to be effective and statistically valid, it will need to be carried out with the full co-operation and involvement of Traveller organisations.



OTHER COMMUNITY SERVICES

...STATISTICAL INFORMATION ON THE USE OF THE MENTAL HEALTH SERVICES BY TRAVELLERS IS SCARCE....THE UPTAKE OF THESE SERVICES IS BELIEVED TO BE LOW... THIS MAY BE DUE TO A COMBINATION OF INAPPROPRIATE PROVISION AND A LACK OF AWARENESS OR CONFIDENCE AMONG TRAVELLERS IN RELATION TO THE SERVICES...

Particular attention has been paid in this Strategy to the provision of dental services. Apart from the importance of improving the provision of dental services for Travellers, it is considered that the proposals for action in the previous chapter can also provide a useful model for improvements in other aspects of the health services. Some of these services are discussed below.

# **Ophthalmic Services**

### 13.2

Ophthalmic services are available to all medical card holders and their adult dependants, through schemes operated by the Health Boards. These schemes entitle eligible persons to have their sight tested, to have spectacles dispensed and to any necessary follow-up treatment where a medical condition is present. Children are assessed at child health clinics and at school health examinations, or can be referred by their general practitioner. Adult medical card holders and their adult dependants can also avail of sight testing and dispensing services provided by private opticians, who have entered into contracts with the Health Boards for the provision of such services.

## **Aural Services**

#### 13.3

Aural services include the provision of hearing tests and where necessary, the supply, fitting and repair of hearing aids for all children up to school leaving age and for all adult medical card holders. Referral to the service is effected through general practitioners, hospital consultants and area medical officers in community care medical services. Prior to June 2000, this service was provided by the National Rehabilitation Board (NRB). However, following the establishment of the Eastern Regional Health Authority (ERHA) and the transfer of functions from the NRB, temporary responsibility for aural services has been assigned to the Northern Area Health Board, pending its transfer to individual Health Boards.

Indications are that, while a reasonable number of Traveller children attend aural services for assessment and treatment, it is very rare for an adult Traveller to do so. A difficulty experienced by the providers of aural services is that it is extremely difficult to keep track of children who have attended. As with other areas of the health services, reminders for follow-up appointments cannot be sent when current addresses are not known.

## **ACTION PROPOSED:**

The Department of Health and Children will seek and act on the advice of the Health Boards and the Traveller Health Advisory Committee on issues relating to the delivery of ophthalmic and aural services to Travellers.

# **Mental Health Services**

#### 13.5

Statistical information on the use of the mental health services by Travellers is scarce. Generally speaking, the uptake of these services is believed to be low and where they are availed of, various problems may be encountered which are similar to those relating to general hospitals (see Chapter 14). This may be due to a combination of inappropriate provision and a lack of awareness or confidence among Travellers in relation to the services. Other problems include poor compliance with medication and treatment regimes (due to literacy difficulties), early self-discharge against medical advice, poor attendance at follow-up clinics, difficulty in providing services to nomadic families and difficulties in hospitals when large groups of relatives come to visit.

#### 13.6

It has also been said that some Travellers may have unrealistic expectations of the psychiatric services (particularly in terms of influencing the provision of accommodation or furniture) and that nursing staff occasionally feel threatened when doing outreach work on halting sites.

- The Traveller Needs Assessment and Health Status Study proposed in Chapter 5 will include consideration of Travellers' awareness of mental health services and will also explore the effectiveness of existing services.
- Primary Health Care for Travellers
  Projects will be involved in a
  programme of education/information
  regarding the psychiatric services
  including the development of
  appropriate information packs.
- Formal links will be created between community psychiatric services and Traveller organisations in each Health Board area to facilitate early intervention

- Specific training in Traveller identity and culture will be provided to mental health service providers in order to ensure that such cultural factors are fully understood in meeting the needs of Travellers in this sensitive area.
- The Department of Health and Children will establish a national working group, representing statutory and voluntary mental health service providers, Travellers and Traveller Organisations to explore culturally appropriate models of mental health services for Travellers.

# **Disability Services**

# 13.7

Little or no information is available on the number of Travellers who have an intellectual, physical or sensory disability. There is also scant information relating to the utilisation by Travellers of disability services, but it appears to be low. This may be due to a combination of inappropriate provision and a lack of awareness or confidence among Travellers in relation to the services.

## 13.8

It has been suggested that Travellers with disabilities may suffer from being an almost invisible sub-group within the Traveller community, lacking in community support services such as home help, occupational therapy and physiotherapy. Because of difficulties of accessibility of Travellers' accommodation, those with disabilities may become institutionalised inappropriately at an early age, with little account being taken of their particular cultural identity as Travellers.

Where children with a hearing disability are taught sign language, the THAC has recommended that facilities should also be put in place to teach their parents sign language, to encourage such parents to avail of all relevant programmes and to ensure that any necessary adaptations to the programmes will be formulated in consultation with Traveller representative bodies.

### **ACTION PROPOSED:**

- Early intervention services for traveller children with an intellectual disability will be designed and delivered in a culturally appropriate way.
- Training and support will be provided to parents of children with an intellectual disability, including increased access to respite and day care services.
- A programme of outreach services developed to support Traveller families with special needs in the area of Metabolic Disorders, will be recognised by the Intellectual Disability Services. Shared care for some conditions (eg. Galactosemia) will be provided by the national paediatric units and local community services.
- Needs and Health Status proposed in Chapter 5 will include an estimate of the numbers of Travellers with a disability and the appropriateness of current service provision.
- In 2002 The Department of Health and Children will develop and monitor an initiative to ensure that the services for those with a disability are sensitive and responsive, in a culturally appropriate way to the special needs of Travellers.

- The Department of Health and Children will consult with the Department of Education and Science regarding the teaching of sign language to parents of Traveller children who have a hearing disability, as described at paragraph 13.9 above.
- Primary Health Care for Travellers
  Projects will develop health education
  modules for the Traveller community to
  inform them of the range of services
  available for those with special needs
  and disabilities.
- New approaches to support services will be developed including the training and employment of Traveller care assistants and home helps.
- The needs of the individual and the family must be taken into account when planning services for Travellers with a disability. A programme will be developed to ensure that individuals with a disability are supported where appropriate to remain within their home environment.
- The liaison mechanism with the
  Department of the Environment and
  Local Government proposed in Chapter
  4 will address and monitor the issue of
  appropriate accommodation for
  Travellers with disabilities.

## **Allied Health Services**

Early identification of speech and language disorders in children is important and early intervention in this area can lead to an improvement in a child's quality of life and a reduction in secondary disability. A compounding problem is the low uptake of the available aural and speech and language services by the Traveller community. A study carried out in the Western Health Board region in 1999 found that a significant number of the pre-school Traveller children assessed presented with delayed speech and language skills. ("Profile of Speech and Language Skills in Pre - School Travellers. June 1999 - Speech and Language Therapy Department, Western Health Board ). While the assessment tools used for the study were appropriate, a need was identified for the implementation of a programme targeted at the stimulation of speech and language skills in pre - school children.

#### **ACTION PROPOSED:**

A National Working Group will be established consisting of a Speech and Language Therapist, Psychologist, Aural Health professionals, and representatives from the THAC. The Working Group will address the following recommendations:

- The inclusion of a question in the Needs and Health Status study on barriers to access, appropriateness and utilisation of these services by Travellers.
- The development and piloting of culturally appropriate therapeutic and assessment materials for Travellers.
- The development of new initiatives to increase the uptake of aural screening services during the first two years of a Traveller child's life and the implementation of a national training programme in the pre-school setting targeted at the stimulation of speech and language skills in pre-school children.

# **Child Care and Family Support Service**

#### 13.11

The Traveller Health Advisory Committee has advised that Travellers do not have access to the full range of Health Board social work services. In particular, there is a lack of adequate resources to support early recognition and intervention when dealing with Traveller families who are at risk.

## 13.12

There are insufficient culturally appropriate care placements for Traveller children and a lack of real choice concerning such placements. To date, it has not been possible to track or monitor Traveller children in care, since data collated does not include information on ethnicity. In the Eastern region, "Traveller Families Care" operates a shared caring service whereby Traveller families foster Traveller children.

### 13.13

A Shared Rearing Service was established in 1991 in the then Eastern Health Board area as a special fostering service for Travellers. The Report of the Working Group on Foster Care ( 2001 ) recommends that other Health Boards should assess the need for special fostering arrangements for Traveller children in their area and that a Shared Rearing Service be developed jointly by the Health Boards as the numbers of children may be quite small and placements may need to be made outside their own Health Board area.

No data or information is available on the extent to which the existing services for older people meet the needs of the Traveller community....only 1% of the Traveller population may be over the age of 65, in comparison with 11% of the settled population.

- Taking due account of existing legal provisions, the Department of Health and Children will examine the implications of providing a designated Social Work Service for Travellers in each Health Board Area with a significant Traveller population. The role of these social workers will be broader than Child Care commitments and will include an involvement in a multidisciplinary team comprising additional Social Workers, Public Health Nurses, Traveller Community Health Workers, Childcare workers and Family Support workers. Traveller organisations, Area Medical Officers, Designated Family Therapists and counsellors will be consulted as appropriate. The objective of this team will be to provide early identification, support and intervention for Traveller families
- Culturally appropriate preventive services such as youth projects, family support projects and parenting courses should be provided.
- The recommendations of the Working Group on Foster Care (referred to at paragraph 13.13 above) will be implemented as soon as possible.
- Traveller children will be identified on childcare and fostering records where appropriate to identify the numbers of Traveller children in care and facilitate the tracking and monitoring of these children through the care system.
- Recommendations from the research currently being conducted in the Eastern region by the Traveller Health Unit into the experience of Travellers in care will be considered.

# **Services for Older People**

# 13.14

No data or information is available on the extent to which the existing services for older people meet the needs of the Traveller community. As outlined in figure 3, only 1% of the Traveller population may be over the age of 65, in comparison with 11% of the settled population.

- Each Health Board will develop an age profile of its local Traveller population.
- Older Travellers will be identified on all health record systems.
- The care of older Travellers will be included as part of the caseload for designated PHNs for Travellers.

# **Community Welfare Services**

#### 13.15

The Supplementary Welfare Allowance (SWA) scheme is administered through Community Welfare Officers (CWOs) in the Health Boards on behalf of the Department of Social, Community and Family Affairs (DSCFA). The scheme provides assistance to any person whose means are insufficient to meet their needs and consists of a number of different types of payments. These include basic payments, supplements which may be paid in respect of such needs as rent, diet or heating, and exceptional payments which may be paid where, in the opinion of the Health Board, exceptional circumstances exist.

#### 13.16

Throughout the country, Travellers can access SWA in the same way as the general population, through their CWOs based in the local health centres. However, since 1984, in the greater Dublin area a centralised segregated service has existed for Travellers based at Castle Street in Dublin. This service is currently under review with a view to localising the service available to members of the Traveller community.

#### 13.17

It is important that discretionary services in particular are delivered in a manner which is sensitive to cultural differences and within an anti-racist framework. This has implications for various payments including back to school clothing and footwear allowance, emergency supports, once off grants towards accommodation, support for travel to hospital and specialist services.

- Officers by the Department of Social Community and Family Affairs in pursuance of a commitment in the Programme for Prosperity and Fairness will explain provision in relation to awareness of Traveller culture and the principles of antiracism.
- CWOs in border areas will be mindful of the implications of cross border nomadism by Travellers on access to services in the two different jurisdictions.
- Travellers' needs will differ from those of the settled community and specific guidelines governing the issue of discretionary payments to Travellers will be developed in consultation with Traveller organisations.
- Clear and relevant information on discretionary payments will be made available to Travellers in an accessible format
- The Department of Health and
  Children will liaise with the
  Department of Social, Community and
  Family Affairs to address any other
  issues concerning the administration
  of discretionary services to Travellers.

## Alcohol and other forms of Substance Misuse

## 13.18

There is little objective research pointing to the pattern of drug or alcohol abuse among Travellers. However, anecdotal evidence suggests that because young Travellers are frequently denied access to youth clubs and other youth recreational facilities, they are at risk of exposure to alcohol and drug misuse.

## 13.19

The Government's Drug Strategy includes a Cabinet Sub - Committee on Social Inclusion and Drugs, an Inter - Departmental policy group on the National Drugs Strategy, and a National Drugs Strategy team. The National Drugs Strategy 2001 - 2008, "Building on Experience", was published in May 2001. In accordance with the Strategy, Regional Drugs Task Forces (RDTF) will be established in all Health Board areas, including the three

boards in the Eastern Regional Health Authority, by mid-2002. Each RDTF will be responsible for implementing the Strategy in that Health Board. In relation to research, a National Advisory Committee on Drugs is responsible for the co-ordination and undertaking of research into all aspects of drug misuse.

# 13.20

In the context of the Government's National Drugs Strategy, the following are points of concern for the Traveller community:

- The ongoing need to promote awareness among the Local and Regional Drugs Task Forces of the issues for Travellers in relation to drug use.
- The need to ensure the inclusion of Travellers in the plans and strategies developed by the Local and Regional Drugs Task Forces as appropriate.
- The lack of information and awareness among Travellers themselves and drug service providers about the nature and extent of drug misuse among the Traveller community.

#### 13.21

The National Drugs Strategy Team has supported the establishment of the Traveller Specific Drugs Initiative. Under the initiative, a Drugs Co-ordinator has been appointed to carry out work in relation to drugs issues affecting the Traveller community. As part of her work, the Drugs Co-ordinator liaises with Local Drugs Task Forces to ensure that such issues are considered in the context of the implementation of their updated action plans. She will liaise in a similar fashion with the Regional Drugs Task Forces, when they are established. The National Drugs Strategy Team will examine any proposals from the Traveller Specific Drugs Initiative to respond to the problem of drug misuse among the Traveller community that might best be implemented on a cross Task Force basis.

One of the aims of this work is to ensure that the distinct needs of the Traveller community are reflected in the structures which have been put in place to address the misuse of drugs.

The Drugs Co-ordinator is also working with Travellers and Traveller organisations in order to support them in seeking to implement initiatives which respond to the drug issues experienced within the Traveller community.

- The Department of Health and Children will enter into dialogue with the relevant authorities, including the National Drugs Strategy Team to ensure that:
- Any research into Traveller health and lifestyles will include research into the pattern of use of alcohol and drugs. The involvement of the Traveller Specific Drugs Initiative and Traveller organisations is critical to the success of this research.
- Service providers in the substance misuse area will be made aware of the results of the research and the importance of the inclusion of Travellers in the planning and delivery of services

- Travellers will be involved in the design and delivery of targeted substance misuse prevention programmes. Critical to this will be the central involvement of the Traveller Specific Drugs Initiative, Traveller organisations and the Traveller Community Health Workers
- Appropriate training will be provided in each Health Board area for Health Board professionals, support workers and Travellers (including Traveller Community Health Workers where they exist) around education and preventative approaches to substance misuse.
- Local and regional Drug Task Forces, in preparing, implementing and updating their plans will examine issues, including Traveller drug misuse, which should be dealt with in an integrated and coherent manner.

# **Consanguinity and Genetic Counselling**

# 13.22

In genetic terms, consanguinity has been defined as marriage between second cousins or closer. It has been proven in global research that cousin marriage, of itself, is not necessarily harmful and does not cause genetic disease. Only if both partners carry an altered gene will they be at an increased risk of developing a genetic disease with on average, one child in four being affected. In Ireland, altered genes for certain conditions such as cystic fibrosis, PKU, galactosemia etc. are present in the population.

Research also points out that consanguinous marriages have little observed effect on the risk of having an affected child when the altered gene causing the disease is common in the population. In Ireland a gene alteration causing cystic fibrosis is very prevalent in society, being carried by approximately 1 in 19 of the population. Therefore, by chance two unrelated carriers could marry and one in four of their children could be affected by the disease. Given these findings, the placing of limits on consanguinous marriage is inappropriate until studies are conducted to determine the prevalence and cause of genetic disease in the Traveller community.

### 13.24

However, Travellers have for successive generations chosen to marry within their communities, so there is clearly a risk of an increase in the prevalence and incidence of hereditary conditions. A small minority of Travellers are affected by genetic conditions.

#### 13.25

The Report of the Task Force on the Travelling Community recommended an in - depth analysis of issues relating to consanguinity. The Traveller Consanguinity Working Group has now been established and includes a range of specialist expertise including representatives of Traveller organisations. It is expected that the Working Group will publish its findings at the end of 2002.

#### **ACTION PROPOSED:**

- The Department of Health and Children will take account of the findings of the The Traveller Consanguinity Working Group.
- The Department of Health and Children will examine the possibility of making genetic screening and counselling services available in all Health Board areas where there is a significant Traveller population.
- Vigorous efforts will be made to ensure that Traveller babies receive the full

- range of neonatal metabolic screening. If this involves longer stays in hospital post-partum to ensure that babies are not lost to follow up, this will be considered. (See also Chapter 8 regarding maternity services).
- Designated Public Health Nurses,
  Traveller Community Health Workers
  and other relevant personnel will
  receive training in nutrition as it relates
  to the treatment of metabolic disorders
  in order to provide information and
  support to families where a member
  suffers from a metabolic disorder.



# CHAPTER 14

General Hospital Services

...RECENT RESEARCH ON TRAVELLERS IN HOSPITAL INDICATED THAT THERE WAS NEGLIGIBLE REFERRAL RATE BY GPS TO OUTPATIENTS. THIS GIVES RISE TO A SITUATION WHERE TRAVELLERS USE A&E SERVICES AS THIS IS THE ONLY WAY THEY CAN ACCESS A HOSPITAL BED OR AN OUTPATIENT CLINIC...

The UCG / McCarthy Report described some research into the use of hospital services by Travellers. Although the sample population was small, the research results give some indication of the trends and problems associated with the use of these services by Travellers. For example, the research indicates that the general hospital services used most frequently by the Traveller community are Accident and Emergency, Obstetric and Paediatric Services. While Travellers appear to use these services at a greater rate than the rest of the population, they appear to have a lower utilisation rate of other hospital services. Anecdotal information from hospitals suggests that hospital services relating to children are used more frequently than those for adults. The lack of up to date and comprehensive medical records for Travellers is identified as a cause of poor continuity of care in terms of follow up from hospital to community care.

# **Accident and Emergency Services**

#### 14.2

Health Boards have reported difficulties in terms of the pattern of utilisation of Accident and Emergency services. These include:

- Inappropriate use of Accident and Emergency departments, in terms of presenting with conditions which are usually treatable by GPs (owing to a lack of access to 24 hour GP services).
- Overcrowding of waiting rooms due to large numbers of family members accompanying the patient.
- Failure to keep recall appointments (owing to a difficulty with access to postal services by Travellers)
- Refusal of GPs to register Travellers as patients.

These difficulties are not confined to the Traveller population but they merit special attention because of the poor health status of Travellers.

Recent research on Travellers in hospital indicated that there was a negligible referral rate by GPs to outpatients. This gives rise to a situation where Travellers use A & E services as this is the only way they can access a hospital bed or an outpatient clinic. (Research carried out by the Eastern Region Traveller Health Unit - for publication in 2002.)

# **Inpatient Services**

#### 14.4

In the course of the UCG / McCarthy study all health boards reported that the Traveller community has a high uptake of paediatric services and one noted that Travellers generally have a low uptake of inpatient services. Reported difficulties include:

- Overcrowding in waiting areas when relatives of Travellers who are hospitalised keep a constant vigil at the hospital.
- Travellers discharging themselves against medical advice.
- Difficulty in contacting Travellers' GPs in order to provide information concerning follow up treatment.
- There is a lack of understanding of Traveller culture among hospital staff. This can lead to a difficulty in communicating with Travellers.
- Low rate of attendance by Travellers at follow up care.
- Occasional difficulty in discharging patients to poor accommodation and poor hygiene standards.
- ▶ 35% of Travellers reported that they experienced discrimination while using hospital services.

# **Outpatient Services**

#### 14.5

The UCG / McCarthy study also found that Travellers have a low uptake of outpatient services, particularly surgical outpatient services. Health Boards reported that Travellers may attend once but generally do not keep their follow-up appointments for treatment e.g. the removal of sutures. Other problems include:

- Difficulties with records due to confusion of people with the same surnames etc.
- Difficulties in tracing Traveller patients in the event of abnormal laboratory results.
- Travellers having difficulty in understanding instructions for self care.
- Administration of appointments due to change of address and literacy problems.

#### 14.6

These issues all point to the desirability of appointing an appropriate liaison person (possibly the Traveller Community Health Worker) to address issues relating to Travellers' use of hospital services, particularly in areas with a significant Traveller population. This person, who could be a Traveller, would be responsible, in conjunction with appropriate Traveller organisations, for ensuring that hospital staff are adequately trained in Traveller culture, that Traveller patients are identified and offered support and that arrangements are put in place for proper continuity of care and follow up (which could also include assisting Traveller families who may be referred to specialist services outside their Health Board area).

- The feasibility of introducing a Traveller identifier on the Hospital In -Patient Enquiry System (H.I.P.E.) will be examined (see Chapter 5).
- Hospital staff who regularly come into contact with members of the Traveller community will receive training and education in intercultural and anti-discrimination practices and in particular Traveller perspectives on health and illness.
- The feasibility of appointing appropriate liaison persons in hospitals (as described at 14.6 above) will be examined.

- As Accident and Emergency departments make greater use of general practitioner and nurse led triage, every effort will be made to redirect or treat Traveller patients at the most appropriate level.
- As a means of reducing the pressure on Accident and Emergency
  Departments from inappropriate out of hours consultations, recent developments in relation to improved out of hours GP cover will be examined.
- Health promotion programmes for Travellers will include a module covering the appropriate use of hospital services including accident and emergency, in patient and out patient services and maternity services.



# CHAPTER 15

**FUNDING** 

...TO THE GREATEST EXTENT POSSIBLE, TRAVELLER HEALTH UNITS SHOULD HAVE A PRIMARY ROLE IN THE ALLOCATION & MONITORING OF... FUNDS

While the level of expenditure on Travellers' health services has increased in recent years, additional funding will be required to implement this Strategy over the next four years. "Once off" funding will be required for a number of research projects which have been proposed and also to provide relevant training for health personnel, while additional revenue funding will be required on an ongoing basis for the provision of additional staff and other service developments.

15.2

The following are the estimated funding implications of the Strategy's proposals:

" ONCE - OFF" FUNDING REQUIREMENTS							
Year	2002	2003	2004	2005	Total		
In - service Training	£50,000 €63,487	£50,000 €63,487	-	-	£100,000 €126,974		
Research	£250,000 €317,435	£50,000 €63,487	£50,000 €63,487	£50,000 €63,487	£400,000 €507,896		
Total	£300,000 €380,922	£100,000 €126,974	£50,000 <b>€</b> 63,487	£50,000 <b>€</b> 63,487	£500,000 <b>€</b> 634,870		

ADDITIONAL CURRENT FUNDING REQUIREMENTS								
Year	2002	2003	2004	2005	Total			
Traveller Health Units	£300,000 €380,921	£200,000 €253,948	-	-	£500,000 €634,869			
Primary Health Care Projects	£500,000 €634,869	£500,000 €634,869	£500,000 €634,869	£500,000 €634,869	£2000,000 €2,539,476			
Designated PHN's	£200,000	£300,000	£350,000	£350,000	£1,200,000			
	€253,948	€ 380,921	€444,408	€444,408	€1,523,685			
Community	£150,000	£200,000	£250,000	£250,000	£850,000			
Supports	€190,461	€253,948	€317,435	€317,435	€1,079,279			
Other Initiatives	£350,000	£300,000	£400,000	£400,000	£1,450,000			
	€444,408	€ 380,921	€507,895	€507,895	€1,841,119			
Total	£1,500,000	£1,500,000	£1,500,000	£1,500,000	£6,000,000			
	€1,904,607	€1,904,607	€1,904,607	€1,904,607	€7,618,428			

In summary, "once - off " funding of  $\leqslant$ 634,870 will be required over the four year period from 2002 to 2005, while additional current funding of  $\leqslant$ 1,904,607 will also be required in each of the four years. This makes a total additional requirement of  $\leqslant$ 8,253,298, of which  $\leqslant$ 7,618,428 will be required on an ongoing basis.

The total funding includes provision for new initiatives which may be identified in relation to Travellers' health, based on the outcome of research projects, the work of the Traveller Health Units, and the ongoing monitoring of progress in implementing the Strategy.

To the greatest extent possible, Traveller Health Units should have a primary role in the allocation and monitoring of these funds.



# CHAPTER 16

**CONCLUSION** 

...THE DEPARTMENT OF HEALTH AND CHILDREN IS FULLY COMMITTED TO IMPLEMENTING THIS STRATEGY WITHIN THE PERIOD UP TO THE END OF 2005...

The Department of Health and Children is fully committed to implementing this Strategy within the period up to the end of 2005. Its effectiveness, however, will be determined by the willingness of health service staff, administrators, and indeed, Travellers and Traveller organisations, to work to change knowledge and attitudes among the settled community and among Travellers in relation to health issues.

#### 16.2

The last ten years have seen an unprecedented focus on policy in relation to Travellers across a range of Government Departments. This Strategy is designed to move beyond analysis to action, over the coming four years. During this period as more information emerges in relation to Travellers' health needs, some changes of emphasis may be required, with new initiatives being introduced where appropriate.

## 16.3

While this document has emphasised the importance of partnership, awareness and access to services, the implementation of the Strategy must focus primarily on the actual delivery of services to the target population. While the Traveller Health Units will monitor the delivery of services to Travellers and collect data on Traveller health and utilisation of the services, particular attention will be paid to the measurement of service provision under the Strategy itself, by requiring annual reports from each Health Board to the Department of Health and Children accounting for their specific allocation of the funding earmarked for this Strategy.

## 16.4

In this connection, the Strategy will be reviewed annually by the Department of Health and Children in association with the Traveller Health Advisory Committee and the Health Boards (through the Traveller Health Units). In view of the PPF commitment to the monitoring of issues in relation to Travellers, it is envisaged that details of the progress in relation to this Strategy will be submitted to the Government, through the Cabinet Committee on Social Inclusion.

The recently published Health Strategy "Quality and Fairness - A Health System for You" proposes a programme of action to address health inequalities in accordance with the National Anti - Poverty Strategy (NAPS) health programme. Targets in the Programme include reducing the gap in life expectancy between the Traveller community and the general population by at least 10 % by 2007. The implementation of this National Traveller Health Strategy over the coming years will be crucial to the monitoring of progress towards meeting this target and to its ultimate achievement within the timeframe prescribed.

The Department of Health and Children is fully committed to implementing this Strategy within the period up to the end of 2005. Its effectiveness, however will be determined by the willingness of health service staff, administrators, and indeed, Travellers and Traveller organisations, to work to change knowledge and attitudes among the settled community and among Travellers in relation to health issues.



# APPENDIX 1

# MEMBERSHIP OF TRAVELLER HEALTH ADVISORY COMMITTEE

Vir Brendan Ingoldsby (Chair) - Department of Health and Childrer

Ms Brigid Quirke - National Traveller Women's Forum
Ms Kathleen Joyce - National Traveller Women's Forum
Ms Ronnie Fay - Pavee Point Travellers Centre
Ms Missie Collins - Pavee Point Travellers Centre
Ms Rosaleen Mc Donagh - Irish Traveller Movement

Ms Mary Murphy - Southern Health Board

Or Maura O'Shea - Western Health Board

Northern Area Health Board

Ms Mary O'Reilly(replaced - Department of Health and Children

Ms Clare O'Reilly - Department of Health and Children
Mr Tom O'Neill - Department of Health and Children
Mr Peter Lennon - Department of Health and Children
Ms Elizabeth Boland - Department of Health and Children
Mr Paul Brosnan (Secretary) - Department of Health and Children

replaced IVIS Sinead Scanian - Department of Health and Childre

# **PHOTOGRAPHS**

**Inside front cover** Traveller children and their pets (from left to right)

Thomas Joyce, John Joyce, Mickey Joyce and Biddy Joyce

**Opposite Foreward** Traveller women (from left to right) Biddy Doyle, Mary Collins

**Opposite Executive** 

Traveller children in pre-school (from left to right)

Martin Collins, Michael Collins **Summary** 

**Opposite Contents Dunsink / Traveller Boy** 

**Opposite Page 1 Ballyhaunis** 

Page 6 Traveller children (from left to right)

Kathleen Mc Donagh, Sheila Collins

Traveller man / Michael Keenan Page 12

Page 18 Children at Play / Collins Family

Page 30 Traveller women (from left to right) Molly Collins,

Missie Collins, Nellie Collins, Nell Collins

Page 36 Traveller children, Tuam

Page 44 Traveller, Galway

Page 50 Traveller family, Castlebar

Travellers, Tullamore Page 58

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Page 72 P.H.C. Workers (from left to right) Mary Lawrence, Mary Collins,

Bridgie Collins, boy in the middle is Martin Joyce

Page 78 Travellers, Galway

Page 82 Collecting scrap

Page 96 Traveller, Tullmore

**Page 102** Traveller Children (from left to right) Marie McDonagh,

Marie McDonagh, Laura McDonagh, Ellen McDonagh

Travellers celebrating culture **Page 106** 

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Inside back cover Traveller child, Albie Mc Donagh

All photographs taken by Derek Speirs, photographer.

