PRIMARY HEALTH CARE FOR TRAVELLERS PROJECT

Implementation Report 1996-1999

PAVEE POINT

THE PROJECT IS A PARTNERSHIP INITIATIVE

EASTERN HEALTH BOARD

Primary Health Care for Travellers Project

c/o Pavee Point, 46 North Great Charles Street, Dublin 1
Tel: (01) 878 0255 Fax: (01) 874 2626

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CONTENTS

Introduction 1

Background and Context 4

Getting the Project Up and Running 9

Implementation of Project Interventions 16

Outcomes, Lessons and Conclusions 25

Prepared by Dr. Phyllis Murphy
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INTRODUCTION

Travellers Health Status: An Issue of Concern

The publication of *'The Travellers Health Status Study - Census of Travelling People 1986'* (Barry and Daly, 1988), and *'The Travellers Health Status Study - Vital Statistics of the Travelling People'* 1987 (Barry et. Al. 1989) gave rise to considerable concern about the health status of the Traveller community. For the first time, comprehensive data was available regarding the health status of Travellers, and it confirmed the perceptions of Traveller Development organisations such as Pavee Point that a health crisis existed within the Traveller community.

Findings about the Traveller Community included the following:

- A median age of fourteen years compared to the national figure of twenty-seven;
- A general fertility rate of 164.2 per 1,000 compared to 70.1 per 1000 for the settled community;
- An infant mortality rate of 18.1 per 1,000 live births compared to the national figure of 7.4;
- Travellers were only reaching the life expectancy that settled Irish people achieved in the 1940s;
- A low uptake of maternal health services with less than a third of mothers attending hospital by the end of the first half of pregnancy;
- A low uptake of infant health services, in particular immunisation uptake and attendance at development screening examination, both of which were considerably less than 50%;
- High mobility of the Traveller community with only 50% to 60% of infants located by the Public Health Nursing service at the child's first birthday.

Although now 10 years old, this research is the most up to date statistical analysis available on Traveller health and a consistent view presented during the consultations for this report is that although some progress is being made, especially through initiatives such as the Primary Health Care project for Travellers, it is relatively slow and significant challenges remain.

Primary Health Care (PHC): A Community-based Approach

At the International Conference on Primary Health Care held in 1977 at Alma Ata in Russia, the World Health Organisation's holistic definition of health as *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* was affirmed and within that context, Primary Health Care was defined as:

> *"...essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to the community through their full participation and at a cost that the community and country can afford at every stage of their 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 of 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.*
>
> (Quoted in the Primary Health Care, Annual Report 1996)

Within the Alma Ata Conference declarations the social dimensions of health were emphasised and Primary Health Care (PHC) was described as essential to health for all. Since PHC is intended to reach everybody, especially those in greatest need, through actively working with people in the context of their everyday environment. These declarations were made against a background of evidence that health care resources were too concentrated in centralised, professionally dominated, high technology institutions, especially hospitals, at the expense of access to less institutional primary health care at the local, community level. According to the Alma Ata report, the conference emphasised the importance of full and organised community participation and ultimate self-reliance with individuals, families and communities assuming more responsibility for their own health.

In terms of implementation and underlying principles, a paper prepared by the current co-ordinator of the Primary Health Care for Travellers project, outlined the following key features of primary health care provision:

- *"Community participation is at the heart of sustained Primary Health Care (PHC) activity;*
- *PHC is an approach to health philosophy, it is not a package, or a complete defined methodology;*
- *There are no blueprints for success in PHC delivery: only a process or an approach which grows as our understanding of human development increases;*
- *PHC is a flexible system which needs to fit all types of circumstances. It must be adapted to the health problems, the culture, the way of life and the stage of development reached by the community;*
- *PHC needs to be developed as the community develops. It is part of the whole social development process;*
- *PHC in communities means enabling individuals and organisations to improve health through informed health care, self help and mutual aid. It means encouraging and supporting spontaneous local initiatives for health."*

(Quirke, 1994)

In her review of Primary Health Care (PHC) activity, Cronin (1997), highlights the important role of Community Health Workers in the implementation of this approach. She notes that Community Health Workers (CHWs) have been traditional in many cultures for a long time, providing communities with a variety of health related services and having different roles in different societies. The concept of CHWs has been incorporated into the PHC system and, since Alma Ata, CHWs have become synonymous with PHC to the extent, she suggests, that there is a danger in some countries that they may be equated with PHC. Cronin notes that there are four principles attached to the concept of CHWs, namely: equity, prevention, participation and appropriate technology and all of which relate to their role. All CHW projects have the common aim of extending basic health services to the poorest and involving communities in programmes. The role of the CHW incorporates preventative, promotive and curative aspects. Functions should be defined according to what is practicable in local circumstances. The preventative and promotive activities require very focused training and support if they are to succeed. General consensus is that short periods of training do not adequately prepare CHWs for their role.

In spite of a recognition of the value of programmes, such as the Community Mothers Programme, little visible evidence existed prior to the Traveller PHC project of any moves within the Irish health care system towards a full implementation of PHC. (Quirke). In recognition of this gap and the potential for developing the human resources of the Traveller community and for involving the skills of Public Health Nurses, the idea of a PHC project for Travellers was developed by Pavee Point. As detailed in the remainder of this report, this project has in fact demonstrated the success and potential of this approach to enhance health care for marginalised groups such as Travellers.

This Report: Purpose and Approach

It is within the above context that this report is written. It sets out to draw together available documentation on the Primary Health Care for Travellers project - the background, set up, structure and the implementation and outcomes - in order to provide a comprehensive overview of the project's operation and process of implementation for the years 1996, 1997 and 1998. The report is not an evaluation, nor does it present any primary research data on project outcomes. Using existing documentation and feedback from consultations with key stakeholders in the project, the report is an overview of the project which particularly seeks to identify key learning emerging to date.

The methodology for the compilation of this report consisted of the following:

1. Review of all literature and documentation on Pavee Point Health work and the PHC project.
2. In-depth interviews with the project co-ordinator and Pavee Point Community Development Worker.
3. Focus group discussions with the Traveller Community Health workers.
4. Interview with the representative of the Eastern Health Board who was mainly involved in the project.
5. Analysis and collation of all information and feedback.
6. Preparation of a report.

The report consists of five parts.Following this introduction, the next part provides an overview of the background and context of the project establishment. The third and fourth parts present a review of the setting up of the project and the activities implemented. The final part briefly reviews the outcomes of the project, identifies the key lessons learnt and presents some general conclusions regarding further development.

Pavee Point would like to take this opportunity to thank Dr. Phyllis Murphy for her work in preparing this Report.

Back L to R: Mary Lawrence, Mary I. Joyce, Molly Collins, Bridgie Collins, Biddy Collins, Nell Collins, Mary Collins. Front L to R: Tessa Collins, Nellie Collins, Missie Collins, May H. Collins, Nancy McDonell, Kathleen McDonnell.

BACKGROUND AND CONTEXT

Project Background

In outlining the background to the Primary Health Care project for Travellers, a core characteristic of the project emphasised continuously by those involved, is that projects of this type cannot be set up overnight. Of critical importance to the project's success is an appropriate preparatory phase, the nature and length of which will depend on the context in which the project will operate. This point was particularly stressed by the CHWs in their review of the setting up of the project. They noted that the project would not have been as successful if they had simply had a quick information-based health care course and not had the chance to firstly develop their confidence, their ability to engage in critical analysis, and the communication skills to express themselves to their Traveller client group and to the professionals with whom they worked. This viewpoint was reaffirmed by the Chief Executive Officer of the Eastern Health Board who noted in the Foreword to the project's first annual report, "96, *"Community interventions such as those in this Project take time to develop ..."*.

In general all of those involved emphasise the factors that contributed to the success of the preparatory phase of the project. These included:

- Pavee Point's on-going work which is based on a model of partnership between Travellers and non-Travellers and is underpinned by a Community Development approach;
- The experiences and skills developed by a group of Traveller women who had participated on Pavee Point's New Opportunity Programme, supported by FAS;
- The development by Pavee Point of a proposal for a PHC model which, based on their research and experience, would be an effective intervention into improved health care for Travellers;
- The development of the national health policy context to a point which facilitated the Eastern Health Board engagement in a pilot action on Traveller health in partnership with Pavee Point.

Each of these contextual factors involved lengthy processes of development in their own right, and in view of the fact they were vital pre-requisites for the success of the project they are briefly discussed below.

Pavee Point's Community Development Work

Pavee Point (formerly DTEDG) was established in 1983 and is a non-governmental organisation which is committed to human rights for Irish Travellers. The group comprises Travellers and members of the majority population, working together in partnership to address the needs of Travellers as a minority ethnic group who experience exclusion and marginalisation. The overall strategic aim of Pavee Point is to contribute to an improvement in the quality of life of Irish Travellers.

The work of Pavee Point is based on an acknowledgement of the distinct ethnic culture of Travellers, and the importance of nomadism to the Traveller way of life. It is characterised by the use of a community development approach which involves addressing the situation of the Traveller Community from a starting point of collective rather than individual need. It means working with, rather than for, Travellers in a manner that prioritises Traveller participation.

Since 1983, the organisation has, through a range of actions, developed a unique experience of active involvement and on-going analysis of Traveller circumstances and needs. This, together with the experience gained through a range of EU projects has meant that Pavee Point is well placed to play a leading national role in representing Traveller needs and perspectives. Overall the work of Pavee Point is multi-dimensional and has included actions in the areas of education, training, childcare, research, policy analysis, lobbying, representation at national fora, and targeted projects.

In relation to the issue of Traveller health, Pavee Point's community development work have been of central importance. Community development actions have involved capacity building and the empowerment of Travellers to identify and articulate their own health needs and the responses they feel would be appropriate. This work has also sought to demonstrate that the concept of health needs to be understood in a holistic way i.e. '*a state of complete physical, mental and social well-being*' (WHO, 1958). Pavee Point believes that Travellers' living conditions are intimately related to their health status, and a multi-sectoral approach must be the cornerstone of any comprehensive health strategy. Furthermore, in the belief that health is a fundamental component of quality of life, Pavee Point has emphasised that responses to Traveller issues must necessarily locate these issues in the context of the situation of the Traveller community as a whole.

Pre-training and Identification of Health Needs by Traveller Women

Capacity building and empowerment have been core factors in the early development of the PHC approach to Traveller health care. During the consultations for this report, the CHWs noted that a key element of the preparation for the PHC project was the level of pre-training and capacity building which had already been delivered by Pavee Point to the original group of Traveller women. A key feature of this training was its inclusiveness of Traveller culture and not only did this provide skills and personal development but it also empowered them to identify the need for health care skills for Travellers and to articulate their views on how primary health care could meet the health needs of Travellers. This training began in September 1991, when with FAS support, Pavee Point co-ordinated and developed a 30 week New Opportunity Programme for Traveller Women which was attended by 16 Traveller women from 7 different sites on the Northside of Dublin. The overall aim of this course was to introduce and sample skills which would enable Traveller women to identify areas for further training with a view to employment possibilities. The younger women who completed the course were particularly interested in further training in child-care. However, the older women, many of whom had reared large families and were grand-mothers, identified primary health care as an area in which they were interested in developing skills and acquiring information. As one of the CHWs noted in the consultations for this report:

> *"People were saying that Travellers don't use health services, but nobody was asking why? But we knew it was because Travellers didn't have the information. We saw the sheer neglect there was of Travellers health and we felt something had to be done."*

In the case of both groups, a belief existed that this approach would be highly beneficial to their community, but they were also interested in generating an income in Traveller Health Promotion at a later stage.

At the completion of the course, a proposal for a *'Health and Child-care Promotion Course for Traveller Women'* was submitted to FAS Baldoyle, in August 1992. This proposal noted that the experiences and skills developed as participants on the New Opportunity Programme enabled the Traveller women to identify, health and child-care promotion as areas for further skills development and in the long-term for income generating possibilities. The proposal was favourably received and funding was allocated for 16 women for a 30-week period between October-May 1993.

At the end of the course, a proposal was made to the Eastern Health Board for funding for a Primary Health Care Initiative for Travellers in Dublin. Because funding was not available at that time, FAS supported a further 30-week training programme under the New Opportunities Programme which enabled the women to stay together as a team and continue their interest in health care while awaiting approval for the Eastern Health Board funding of the PHC project.

The importance of this relatively lengthy lead-in period to the Traveller women's direct involvement with health care provision is particularly emphasised by the project. Within this pre-training period, the women were facilitated in a process of self-development, empowerment and skill development. In this way they were properly equipped with the range of personal and technical skills necessary for them to effectively carry out their work. Key elements of this vital process included the following:

- Effective teambuilding;
- Time and facilitation to reflect on the work involved in health care provision;
- Development of critical analysis skills;
- Improved communication skills for the effective dissemination of health related information and also for feedback regarding project progress.

Policy Context Development: The National Health Strategy

In parallel with the emerging commitment and interest on the part of Pavee Point and the group of Traveller women to the concept of PHC, new directions were also being considered by the Department of Health. In 1993, the Department began to carry out a review of Health services with the objective of developing a National Health Strategy which would identify and target certain groups who are known to be disadvantaged in various ways and whose health status is shown to be adversely affected. Pavee Point made a detailed submission to the Department in September 1993. The submission, *Towards a Health Strategy for Irish Travellers*, was drawn up in consultation with Travellers through a number of workshops and discussions. It also involved research (funded by the Combat Poverty Agency) which set out to identify and document key issues and make recommendations to the proposed Strategy.

Key points made included the following:

- Excessive reliance is placed on interventions of external agencies;
- Previous research on the health status of Travellers confirm their low life expectancy, high infant mortality rates, and high rates of morbidity and provide valuable baseline information, but they need to be complimented by Travellers own perceptions of their health needs and priorities;
- A community response involving Travellers as trained primary health care workers would eliminate the cultural distrust between health care providers and the recipients of that care;
- A review of some of the relevant international literature on health status of ethnic groups illustrates how complex the issue is, and that it relates not only to material socio-economic conditions but also to concepts of cultural validity and relevance and to issues of discrimination, marginalisation and racism and their effects on the health of the whole minority community;
- Issues identified as needing to be urgently addressed included: access to medical care and qualification for medical cards, access to specialist services including dental services and the racism of some health care workers.

Among the recommendations made was the development of a primary health care service where Travellers themselves are trained as primary health care workers with the support and supervision of qualified nurses and doctors. The submission provided a detailed proposal of the relevance and potential of such a model and noted that a proposal to establish a Traveller Health Promotion Service in one part of Dublin was at that time under discussion with the Eastern Health Board. According to the submission:

"It is envisaged that this service would:

- *Establish a model of Traveller participation in the promotion of health.*
- *Develop the skills of Traveller women in providing community based health services.*
- *Liaise and assist in creating dialogue between Travellers and health service providers in the area.*
- *Clarify gaps in health service delivery to Travellers and work towards reducing inequalities that exist in established services."*

The submission noted that such a programme would enable the workers to make use of the kinship networks to introduce new ideas, such as methods of family planning: a most effective way of doing this work. The Primary Health Care Workers would also serve as role models for other members of the community. Adequate supervision, support, evaluation and training for the workers were emphasised as key components in such a strategy.

In March 1994 the Department of Health published the *National Health Strategy* Report. In it commitments were made by the Department that a special programme would be implemented to address the particular needs of the Traveller Community, a commitment to consultation with Traveller groups, closer liaison with other relevant statutory and voluntary agencies providing services to Travellers to ensure better targeting of services, and development of models of Traveller participation in health promotion and prevention. In addition, the Health Strategy indicated a commitment to ensure that Health Boards would make special arrangements to encourage and permit Travellers to avail of primary health care services. It was this commitment which facilitated Pavee Point's preparing and submitting a proposal for a Primary Health Care Project for Travellers to the Eastern Health Board in 1994.

Equality and the Health Services

Besides preparing the submission to the National Health Strategy, a further dimension of the preparatory work by Pavee Point was the organising and hosting of a National Conference, '*Equality and the Health Services, The Challenge to Address the Needs of Travellers*', in May 1994. The Conference, for which there was a *'huge'* demand for places, was aimed at two sectors:

1. Those involved in health policy development and planning, and those involved in the delivery of the health services including administrators, nurses, doctors, hospital staff;
2. Travellers and Traveller support groups from throughout Ireland.

The aims of the Conference were:

- To provide an opportunity for Travellers, the voluntary sector and health professionals to come together and share experiences and make practical suggestions about creating greater health equality for the Traveller community;
- To create dialogue between Travellers, the voluntary sector and health service providers and planners;
- For participants to get information on the National Health Strategy and its plans to address Traveller issues;
- For participants to discuss Traveller participation in health planning and services.

The Proposal for The Primary Health Care Project

Building on the preparatory work to-date, Pavee Point and the Eastern Health Board entered discussions on the Primary Health Care Project proposal. The proposal noted that experience in other contexts indicated that trained mothers can participate actively in health problem definition; assessing needs; planning the content and delivery of care; identifying resources; and in monitoring and evaluating the services provided.

The catchement area of Community Care Area 6 was proposed for piloting the project, the rationale for this being that the majority of the women who had been trained resided there, and also the fact that over 250 families were resident in the area, representing a population of over 2,000 Travellers. Highlighting that many of these live in poor conditions, the proposal noted that the situation of Traveller women, trying to rear children, is particularly intolerable.

Within that context the proposal requested funding from Eastern Health Board to support, co-ordinate and manage a Traveller Health Promotion Service for Travellers living in the Finglas/Dunsink areas of Community Care Area No. 6. It was noted that a group of Traveller women had already received training in basic health issues and now had the personal skills to engage in peer health care support.

The following structure was proposed:

The "Traveller Health Promotion Service" would be co-ordinated and managed by Pavee Point. A small steering group would be established representing Traveller and settled people from Pavee Point. A representative of Community Care Area No. 6 would also be invited to be a member of the steering group. The steering group would monitor the on-going work and development of the service.

The service would:

- Establish a model of Traveller participation in the promotion of health;
- Develop the skills of Traveller women in providing community based health services;
- Liaise and assist in creating dialogue between Travellers and health service providers in the area;
- Clarify gaps in health service delivery to Travellers in Community Care Area 6 and work towards reducing inequalities that exist in established services.

The programme would be supported on the ground by a worker from the Eastern Health Board, who would work in partnership with the Pavee Point Steering group and the women involved in the development of this service on the sites. The pilot service would be delivered to 60 Traveller families initially for a year and then be evaluated. The Traveller women would work in 4 pairs (i.e. 8 women) and each pair would work with 15 families for a period of 2 mornings or eight hours per week (as appropriate). It was envisaged that the target families would be from Avila Park, Cappagh Field, Dunsink Halting Site, St. Mary's Park and Roadside Dunsink.

Besides highlighting the innovative nature of the programme, the proposal noted if it was successful it had the potential to be replicated in other community care areas and other Health Board regions after an evaluation. With the approval of the proposal, planning commenced for a new partnership Primary Health Care Project for Travellers, the first of its kind in Ireland.

GETTING THE PROJECT UP AND RUNNING

Commencement

Following the successful application of the Pavee Point project proposal, the project officially commenced on 10th October 1994. The project was undertaken on a one year pilot basis in the Finglas/Dunsink area. The CHWs were funded for 40 weeks of this 52 week time frame but it was envisaged from the outset that the time frame would be extended.

The project set out to use community development strategies to achieve the involvement of Travellers in identifying their priority health care needs and the barriers they experienced regarding access to core health services.

In line with this aim, specific objectives were developed, an appropriate project structure was set up, and agreement on workable time scales for project interventions was reached. Each of these dimensions are briefly outlined below.

Project Objectives

The Primary Health Care for Travellers Project initially had four core objectives. During the second quarter of the project these objectives were expanded into specific objectives in order to enhance project implementation, evaluation and time management. The four core objectives were:

1. Establish a model of Traveller participation in the promotion of health.
2. Develop the skills of Traveller women in community based health services.
3. Liaise and assist in creating dialogue between Travellers and health service providers in the area.
4. Highlight gaps in health service delivery to Travellers in Community Care Area 6 and work towards reducing inequalities that exist in established services.

Location

The Primary Health Care project was piloted in Community Care Area 6. The Project targeted the Traveller residents of five sites. These sites were:

1. Avila Park (Group Housing Scheme).
2. Cappagh Field (Temporary Site).
3. Dunsink Halting Site (Official Site).
4. Roadside Dunsink (Unofficial Site).
5. St. Mary's Park (Group Housing Scheme).

These areas were chosen because the Community Health Workers were most familiar with them and they represented a cross section of the range of accommodation options available to Travellers. There was a total of 89 families resident in these sites and they were the targeted beneficiaries of the Project.

Management, Co-ordination and Staffing

Overall responsibility for the PHC Project rests with the Eastern Health Board and the management of Pavee Point who appointed a steering group. The Steering Group which consists of:

- two Eastern Health Board representatives (The Public Health Nurse and the Eastern Health Board administrator);
- two Pavee Point representatives (Health Co-ordinator and Director);
- two Traveller women (one permanent and one rotating);
- a Technical Advisor (Trinity College Dublin).

The role of the group is to oversee the implementation of the project and meetings take place on a monthly basis to review progress and plan for the future.

Two project co-ordinators, one a community worker from Pavee Point, and one a public health nurse assigned by the Eastern Health Board were appointed to the project. They shared responsibility for day to day management and project co-ordination. The public health nurse reported to the Superintendent within the Eastern Health Board while the community worker reported to Pavee Point and was accountable to its management committee.

The eight community health workers were selected from among the Traveller community, on the basis that they had participated in previous training with Pavee Point and had shown an interest in health issues. They were mothers of large families and representatives of the target areas. Many of them were pre-literate. During the pilot phase, which was the first year, they worked a 12 hour week for 40 weeks. The community health workers reported to the two co-ordinators and to each other.

The role of the CHWs was defined as follows:

1) To access and disseminate health information to the Traveller community and contribute to the promotion of health.
2) To increase Traveller participation in health issues and develop an advocacy role in their community.
3) To facilitate dialogue between health service providers and the Traveller community and to promote knowledge and understanding among health authorities to make appropriate provision for Travellers.
4) To contribute to a response to policy initiatives which impact on Traveller Health status.
5) To contribute to the development of health education materials appropriate to the Traveller community.

6) To take positive action to ensure the specific health needs of Traveller women are addressed.
7) To liaise and work with other relevant statutory and voluntary organisations as appropriate.
8) To be responsible and accountable to the co-ordinators of the project.

Evaluation

In view of the pilot nature of the project and its potential for replication in other areas, it was recognised that evaluation should form a core component of the project structure and process. Through the support of the Director of Community Care in Area 6, a part-time evaluator, who was an Eastern Health Board doctor was made available to the project in November 1994. Subsequently an evaluation team consisting of the part-time evaluator and a technical advisor, who was a public health physician with development experience from the Department of Community Health and General Practice at Trinity College, was approved by the steering committee. From the outset it was recognised that in view of the time-scale of the project, evaluation expectations had to be realistic and also that the evaluation plan must address the process of Traveller participation in health care as much as evaluating outcomes in the health status of the Traveller community. In this context, the evaluation plan which was agreed for the project involved a variety of tools including a baseline Traveller health survey designed by project staff and evaluators.

Project Implementation

Within this agenda of work, three key work areas were actively prioritised during the project: the training process for the CHWs; the Base line survey; and the consultative process for setting the project agenda at the end of the set up phase.

❑ Training and Planning

Although the CHWs had participated in three training courses prior to the project, capacity building and training continued to be core elements of the project. An initial needs assessment, with particular emphasis on the identification of health needs by the Traveller workers, resulted in a plan for training inputs. This plan reflected the importance of this on-going training process both personally and technically for the women. Through it they were enabled to develop their team working skills, have a structured opportunity to reflect on their work, and also provide support to each other. Training sessions also provided a forum through which new ideas and issues could be introduced and developed by the group.

The training provided consisted of experiential learning, group discussions, lectures, skills workshops, and project work. Visits were organised to health facilities and to other groups. Group discussion was designed to facilitate self-expression and the development of the communication skills needed to implement the project actions. There was consistent variety of input in the training, and use was made of audio-visual media such as videos, slides and photography. Drama, role plays, drawing and simulation exercises were also used.

The project planning process was ongoing and integrated as a participatory training activity. The community health workers were involved in each step of the project planning and had the main role in decision making with the co-ordinators acting as facilitators. Reviews were built into the programme enabling assessment and adjustment. The emphasis was on dealing with issues as a group. There were some problems such as absenteeism and poor levels of punctuality but these were addressed by the group. Some difficulties arose due to the differing expectations of the

various partners but the review feedback mechanisms were able to deal with these in such a way that they became opportunities for programme development rather than constraints.

As part of the planning process the CHWs visited the local health centres and hospitals in order to familiarise themselves with the services that were available, and the procedures that needed to be negotiated in order to access these services. This was emphasised as particularly important in the consultations with the CHWs (for this report). They emphasised that even if services are located beside them Travellers have very little information about what goes on inside the buildings. As one of the CHWs noted:

> *"I couldn't believe it when we did the tour of the clinic. After being 20 years in the area and living a mile up the road I didn't know there was speech therapy and child psychology. You wouldn't know these things if you are just in and out the odd time."*

Information for the project was also collected by the public health nurse, from other service providers to the Traveller Community e.g. teachers, social workers, adult literacy teachers and area administrators.

❑ Baseline Survey

A survey of the health problems and needs of Travellers in the project area was perceived to be essential if appropriate prioritisation of activities was to occur.
The following objectives were identified for the survey:

- Provide a baseline of information about Travellers (i.e. to give a baseline of disease pattern and utilisation of service at the time before starting the programme);
- Inform policy making at all levels of the Eastern Health Board;
- Ensure the development of culturally appropriate and sensitive health services for Travellers;
- Inform the Traveller community of the findings regarding their health and illness experience;
- Enable Travellers to participate in the planning process.

A questionnaire was developed by the eight CHWs in conjunction with the project co-ordinators and the two project evaluators from the Eastern Health Board and the technical advisor from Trinity College Dublin.

The questionnaire was piloted with 9 Travellers, who were attending training at Pavee Point, and were from outside the target areas. Two issues were identified for the successful implementation of the survey: the need to stress confidentiality and to give Travellers permission to refuse to participate in the questionnaire.

The CHWs visited the site where it was planned to carry out the survey a week in advance to let the residents know of the intended visit. A total of 89 families were identified on the five sites to participate in the survey. Only one woman refused to answer the questionnaire, giving a total of 88 completed questionnaires. All the five sites were surveyed simultaneously. It took four months to complete the baseline survey.

The success of the survey implementation was perceived to be due to the involvement of the Traveller women and their experienced sensitivity to their own community. The completion of the baseline survey by the Traveller community health workers was important because the participatory process that was facilitated was one of the first steps towards Traveller community involvement in primary health care. This survey helped the community health workers to practice some of the skills acquired during the training (e.g. interview technique, listening skills etc). and also afforded them and the Traveller respondents the opportunity to reflect on their own health experience and to share

it with each other. During the consultations for this report the CHWs spoke of their initial fears at setting off to interview their own community. As one person reported:

> *'When we were starting off, it was a bit overwhelming, we had a big fear of not being accepted. We were very nervous but we needn't have worried. They accepted us because we were one of their own and we gave them feedback. Travellers were getting tired of people taking information from them and not feeding it back to them.'*

Focus group discussions were used in conjunction with the questionnaire for needs assessment of the target areas. The purpose of the focus group was to explore, through informal discussion, the perceptions held by Traveller women of the barriers to accessing health services and how to overcome them.

❑ Setting the Work Agenda: A Consultation Process

Reflecting the commitment of the project to community participation and inter-sectoral collaboration, consultations were held during the final stage of the project. Three consultation sessions were held:

- One session with Travellers from four of the targeted sites;
- One session with Heads of Disciplines (health Service Providers) from Community Care Area 6;
- A joint consultation meeting with Travellers and the heads of relevant health disciplines.

Each of these sessions involved presentation of feedback from the baseline survey, discussion of progress to date, and a setting of priorities for further development.

Over the following summer period, bi-lateral discussions took place and priorities for interventions over the following year were agreed in relation to actions involving:

- Public health nursing - facilitating dialogue and liaison, providing back up support and training on intercultural awareness, ensuring a focus on women's health;
- Environmental Health - establishment of relationships with environmental officers, facilitating information inputs, a joint promotion and information dissemination role, assisting in preparation of a form for documentation of environmental hazards;
- Dental health - establishing structures for dialogue between CHWs and dental personnel, developing and expanding Traveller access to, and utilisation of, services, increasing inter-cultural awareness and designing a dental health education poster.

Outcomes and Conclusions at the End of the First Year

On a practical level a number of outcomes were evident from the first year of the project. Project reports record that significant progress was made in relation to:

- The capacity of the Traveller women who were employed as CHWs and the development of their skills in relation to health promotion work;
- The gathering of information on the health status of the Traveller families on the project sites, on the health service personnel and services mainly used by these families and on disease pattern and uptake of health services;
- The development of effective inter-sectoral collaboration. The steering group demonstrated the joint collaboration necessary for the initiative to progress;
- A considerable impact was made on Travellers and Traveller organisations around the country about the potential of health initiatives among the Traveller community;
- Greater awareness was created among health service practitioners and policy makers about Traveller culture, the specific needs of Travellers and the possibilities regarding service improvements.

In the light of these positive evaluations, the overall conclusion at the completion of the first year of the project was that it should be continued for a further 4 year period.

Since then the project has been funded on a yearly basis and, as will be outlined in Section Four, the project objectives continue to be implemented.

Contextual Changes at National Level

In the project's first annual report (1995), it was noted that during the initial pilot phase of the project: "*a significant and welcome shift took place in the national policy context of Travellers and health issues*"'.

In June 1995 the Department of Health published a discussion document *"Developing a Policy for Women's Health".* In view of the fact that this document made specific reference to the health needs of Traveller women and to the PHC project for Travellers, Pavee Point prepared a response document which particularly welcomed the following points made in the Department's document:

- A precondition for reducing premature mortality and unnecessary morbidity among Traveller women is an improvement in their accommodation;
- Houses should be provided for those Travellers who wish to live in a house. Serviced sites should be provided for those who wish to retain the traditional Traveller way of life;
- Health Boards should ensure that health services are provided to Traveller women and children, with a special emphasis on maternal and child health.

In July 1995, the Report of the Task Force on Travelling People was published and it was welcomed by Pavee Point as one of the most comprehensive overviews of the situation of Irish Travellers. In a chapter on health, recommendations were made on a range of Traveller specific services including the PHC project activities to which the following references were made:

> *"Peer led services (such as Traveller paramedics) such as that piloted in the Eastern Health Board, should be expanded*".
>
> *"Primary Health care services for the Traveller community should be delivered on an outreach basis*".

"Traveller support groups have an important contribution to make in the targeting and in the appropriate delivery of health services to the Traveller community".

"A regular conference of service providers and Traveller organisations should be organised by the Department of Health to facilitate the transfer of experiences of Traveller specific services between Health Boards".

"All professionals should receive training on the circumstances, culture of and discrimination practised against Travellers, as part of their training. Service providers in frequent contact with Travellers should receive more in-dept training in intercultural and anti-discrimination practices. This training should also include a focus on Travellers' perspectives on health and illness. Travellers and Traveller organisations should be resourced to play an active role in this training and education".

In relation to health services a key recommendation of the Task Force was that: each Health Board should establish a Traveller Health Unit with a specified brief and with a committee drawn from the various sectors in the Health Board and from local Travellers and Traveller organisations.

In relation to these and other recommendations, the Task Force report stressed that in the implementation of recommendations, Traveller specific services *"should be designed to complement mainstream services and to improve Traveller access to these".*

Overall the Task Force recommendations were an affirmation of the PHC project's work and in particular of the contribution it was making to an overall development of Traveller health services.

IMPLEMENTATION OF PROJECT INTERVENTIONS (1996-1999)

Project Interventions

On the completion of year one, a challenging agenda of work was agreed for the further development of the PHC project and by 1996 actions were underway. In line with the underlying community development ethos of the project, training and capacity building of the CHWs and the participative planning process continued to be core elements of the project.

Over the period 1996 to 1999, an extensive range of actions were implemented. In view of the volume of work involved in these activities and the time and resources needed to engage in detailed recording and documentation, it was not possible for the project to document all elements of activities and outcomes which took place. However, this section will attempt to present a brief overview of the main achievements of the project, particularly those which represented the interventions agreed within the project workplan and, where available, outcomes which were identified by the project evaluation (Healy, 1997).

Work With Public Health Nurses

The specialist Public Health Nurse (PHN) appointed to the project area in mid-August 1995, continued to work with the targeted families. The evaluation report (1997) notes increases in uptake of such services as developmental examinations in the mobile clinic, and referral to specialist services such as speech therapy, and suggests that this demonstrates a positive impact of the specialist PHN. The report also highlights that the CHWs have been of considerable assistance to the specialist PHN, in providing introductions to families in the area, building up Traveller confidence in the system, delivering appointments and reminders and stressing the importance of developmental check-ups. One particularly important intervention arranged and piloted by the CHWs, in co-operation with the specialist Public Health Nurse involved audiology (hearing) tests for children within the project areas. The uptake of appointments in this intervention was 99%, with 85% of those who attended being referred on to the ENT Department of the Children's Hospital.

The CHWs also assisted in the delivery by Pavee Point of an in-service workshop for Public Health Nurses and other health service providers working with Travellers. This workshop was held in order to provide an opportunity for Public Health Workers to come together and share experiences and make practical suggestions for addressing the health needs of Travellers.

The effective operation of a specialist Public Health Nurse (PHN) to the project area was perceived to have been a particularly important element of the PHC for the following reasons:

- *The Travellers have a key person to identify with in order to link with other services;*
- *The specialist PHN can move with families from one part of the area to another;*
- *The specialist PHN can organise clinics and records to suit the client group in collaboration with the mobile clinic staff, Area Medical Officer and Travellers;*
- *Continuity of care is enhanced because, over a period of time, the specialist PHN becomes familiar with the extended kinship network and can use this information for the dissemination of information.*

(Healy, 1997)

Dental Services

A number of activities have been carried out in relation to the enhancement of dental service to Travellers. These include the following:

- Training sessions on dental hygiene have been given to the CHWs since the beginning of the project;
- An in-service workshop on "Oral Health and the Traveller Community" was held in 1996 and provided an opportunity for dental personnel from the Eastern Health Board to come together, share experiences and make practical suggestions;
- The Community Health Workers have developed a close liaison with local dental services on an on-going basis (via the dental educator) and have been actively engaged in distributing appointments and encouraging Traveller uptake of dental services. This work has helped to raise consciousness among Travellers of the importance of dental health and has also raised service expectations among Travellers;
- Two Traveller specific evening clinics providing dental care from local health centres have been established and have resulted in an excellent uptake in services. The project evaluation (1997) notes that organisation of block bookings for Travellers from the project area to attend the dentist at Roselawn Health Centre, increased from 0% to 80% attendance at dental services before and after project. Adults not only attended for initial appointments but returned for further treatment;
- The Primary Health Care project organised special sessions with Traveller mothers of the under 5 years age group;
- Themes was identified for dental posters, two of which have been produced with support from the Dental Health Board.

Environmental Health

The project sees this area as critical to the success of Primary Health Care as it is believed that unless accommodation conditions improve there will be little impact on Traveller health status. While an intervention had been developed which included site maps which identified hazards, unfortunately only a small amount of work has been undertaken in this area due to an on-going dispute between the Environmental Health Officers and the Eastern Health Board. Based on discussions between the Community Health Workers and the Environmental Health Officers, prior to the dispute, it had been decided that work in the areas of rodent pest control and refuse would be prioritised.

Early in 1997 the Community Health Workers met with officials from the Department of the Environment, to raise awareness of poor living conditions on some sites in the project area and to highlight the need for provision of technical advice on matters such as scrap management. The preparation of videos on environmental issues was also recommended.

Nutrition

The aim of this intervention is to empower Traveller women to make healthy food and cooking choices. All the actions in this intervention are based on previously identified needs of Traveller groups. Because this area has remained largely unexplored, the intervention has been flexible in order to incorporate new issues as they arise. Among the actions that have taken place have been:

- A five week 'Healthy Eating' course for the Community Health Workers;
- A supermarket tour, arranged by the Community Nutritionist in order to discuss shopping habits, to look at ways to improve shopping and to provide assistance with labelling;

- The development of educational materials on nutrition;
- Cooking sessions on preparation of low cost healthy recipes, and demonstration of the use of herbs, fruit and vegetables.

It is worth noting that the delivery of this intervention took twice as many sessions as planned. As suggested by the evaluator in her report (1997), this highlighted the need to impart new information slowly and consolidate that which has been learnt at regular intervals.

Development of Appropriate Health Education Materials

An important action of the project was the production of culturally appropriate education materials. The rationale for this work included the following:

- To provide a Traveller visibility in health education materials;
- To give Travellers confidence to engage in recommended health practices e.g. give Traveller women confidence in breast-feeding through visual role models of other Traveller women breast-feeding;
- To provide culturally appropriate education materials for health service locations such as doctors waiting rooms, in order to make Travellers feel more comfortable;
- To provide alternative education materials to those which presumed literacy among the target group.

In consultation with Travellers and with a high degree of involvement of the Traveller CHWs, videos and posters were produced by the project.

Two videos were produced, *Primary Health Care for Travellers* (1996) and *Pavee Beoir: Her Reproductive Health* (1998).

- *Primary Health Care for Travellers* focused on reviewing the PHC project background and implementation, with a view to dissemination of the value and appropriateness of this approach for the promotion of health care among Travellers.
- *Her Reproductive Health,* aimed to promote Traveller women's health education in relation to reproductive health. The video, which demonstrated the work of the CHWs in supporting and encouraging Traveller women, was divided into four individual sections, Cervical Screening and Breast Self-examination; Family Planning; Ante Natal and Post Natal Care and The Menopause. In conjunction with a set of accompanying workbooks (also prepared by the PHC project), the video has been used for Traveller women's health training courses.

A total of eight posters were produced by the project. Initially the project had difficulty getting funding for the production of Health Education posters and designed and funded four posters from project resources. These were:

- *Travellers Health* which sought to disseminate information on the health status of Travellers;
- *What You Should Do With A Burn* which provided diagrammatic advice on what to do and not to do;
- *Why You Should Breast Feed Your Baby,* which again used visual information to promote the benefits of breastfeeding;
- *Why You Should Give Your Child The Needle* which used visual information to educate as to the diseases that can be prevented by immunisation.

The posters were designed for use by Traveller groups in culturally appropriate health education strategies with Travellers; for display by Traveller organisations in their premises to raise awareness of health as an issue; for display by health service providers in health clinics and surgeries to create a Traveller relevant environment.

These posters were viewed as extremely successful by the project, by the Eastern Health Board and by others engaged in health education. Feedback particularly highlighted the impact of the graphics and pictures in getting the message across and the value of this approach for audiences wider than the Traveller community. As a result, funding was provided by the Eastern Health Board for 2 further posters which were on nutrition. Also two other posters were produced on Dental health with support from the Dental Foundation.

Although not specifically a health education material, an important resource used by the project was a quilt which was prepared by the group in 1995. This quilt represented different aspects of the project i.e. dental, environmental, cures etc. as prioritised by the CHWs. It was used both in Pavee Point as a backdrop to workshops and seminars and also on visits to Traveller Groups. It was a particularly effective information channel on the project to those with poor literacy skills. The quilt was used as the cover page of the first annual report and over the development of the project has come to be a symbol of the project.

In-Service Training Workshops and Conferences

As a strategy to help facilitate the provision of culturally appropriate health services for Travellers, in-service training is considered a key part of the project's work. While this work is part of the wider national agenda of Pavee Point, the PHC project has played a major role in delivering a range of in-service training actions. It has drawn from the project's experiences and usually incorporated the CHWs. Two levels of in-service training have been delivered by the project:

❑ **In-service Training to Health Professionals: which included two strands**

(i) Thematic workshops at Pavee Point to which health professionals have been invited. These have focused on:

- Training on racism, Travellers' culture and Travellers' health needs with health professionals;
- In-service workshop for Eastern Health Board Dental personnel (April 1996);
- A national in-service workshop for public health nurses who work directly with Travellers (April 1996);
- A Health Strategy Workshop for Voluntary Organisations working with Travellers (April 1997);
- An In-service Workshop for Health Professionals and the Traveller Community (November 1998).

The aim of these workshop was to provide opportunities for health personnel to come together, share experiences and make practical suggestions for addressing the heath needs of Travellers within their specific area of work.

The objectives were:

- To create dialogue between health personnel and Travellers;
- To provide information on the situation of Travellers and increase awareness and understanding of Traveller culture;

- To explore Traveller health needs and further develop appropriate approaches in working with Travellers;
- To get support through networking and sharing experiences.

The workshops were attended by a range of health personnel who work with Travellers, and programmes typically included inputs on Irish Traveller health and current health issues with a particular focus on health services. Exercise and discussion sessions provided participants with opportunities for discussion and exploration.

Feedback from the workshops was very positive with evaluations emphasising in particular the value of the opportunity for health care professionals to meet Travellers and hear their experiences and generally examine their attitudes to Travellers using their services. Very definite intentions regarding improvements in practice were expressed within the evaluations including a greater awareness of language and personal attitudes.

The increased awareness and improved communication resulting from these initiatives contributed to more mutually supportive structures.

(ii) The CHW staff have also sought and responded to invitations to provide this training, in hospitals, including St. Vincents, Tallaght and Blanchardstown, for health professionals including nurses, doctors and a range of health support personnel.

❑ Training to Traveller Organisations

This training has also been provided by the project and with the introduction of the new Health Units, this work is becoming increasingly important in order to enable Traveller organisations to effectively participate in this new development. Training to Traveller organisations has mainly involved:

- Workshops on *'Health needs and Travellers'* for Traveller organisations;
- Training of a technical support nature which has focused on assisting groups to develop their agenda and work processes.

❑ New Approaches for A New Millennium: May 1997

In addition to structured in-service training a number of conference events were also organised by the project. As the Department of Health was developing its national strategy on Travellers health, such a conference was perceived by the project to be a timely occasion to discuss the strategy's content and to reflect on its recommendations. The overall aim of the conference was:

- To bring together key actors in order to progress thinking, practice and policy in relation to Travellers health

The conference brought together a number of different perspectives including:

- People involved in health policy development and planning and in the delivery of health services;
- Travellers and Traveller organisations from throughout Ireland;
- People working in other sectors which have a relevance to Traveller health status.

In addition to an overview of the PHC, papers were presented which focused on the issues of Traveller inclusion in Health Policy (Department of Health), Equity in Health (Pavee Point), Health Service Initiatives for Travellers in the Eastern Health Board region, Primary Health Care strategy (Trinity College Dublin) and Accommodation and Health Status (Department of the Environment). A report is available on the conference.

Special Interventions

In addition to the planned programme actions a number of special activities were implemented within the project. These included the following:

❑ NOW Programme: 1996-1997

This initiative was organised as part of the New Opportunities for Women (NOW) European Community Initiatives and was jointly funded by the Eastern Health Board. The overall aim was to create conditions for Travellers to obtain employment within the Health Service, and in doing so, provide a model that could be more broadly applied in assisting Travellers in accessing the mainstream labour force.

Key actions of the programme were:
- Establishment and provision of accredited Primary Health Care Training Programme to Traveller women;
- The piloting of an innovative training initiative in Primary Health Care for Traveller Women;
- The development of culturally appropriate course curriculum.

The Primary Health Care Training programme was organised over 64 weeks in the years 1996 to 1997. The course was accredited by Trinity College Dublin and the Eastern Health Board and was the first of its type in Ireland. More than half of the course participants were pre-literate. Eight of the trainees were employed as CHWs on their sites, two of whom specialised in the area of women's health and two concentrated on Childcare. A further two women went on to specialised training in a further NOW programme which is exploring culturally appropriate responses to domestic violence in the Traveller community.

❑ Women's Health Initiative

A commitment was made by the National Health Strategy *'Shaping a Healthier Future'* (May 1994) that '*an accessible and comprehensive family planning service would be developed in each health board area on a phased basis*'. The report also acknowledged that Travellers may have specific needs in relation to family planning and made a commitment to *"ensuring that Health Boards make special arrangements to encourage and permit Travellers to avail of primary care services, in particular... family planning.....*'. Within this context and as part of the PHC work, a proposal was submitted to the Eastern Health Board for a Family Planning Initiative with Travellers. The proposal highlighted the Task Force findings of a low take up of post-natal services and a low rate of family planning and suggested that the participation of a Traveller project in identifying the issues and needs for Travellers in family planning would ensure that an appropriate and culturally sensitive response would emerge.

The overall aim of the project was:

- To create the conditions for better access to family planning services by Travellers.

The objectives were:

- To research the contraceptive needs and issues for Travellers;
- To develop appropriate health education materials;
- To provide training to Travellers as family planning facilitators;
- To provide in-service training and advice on Travellers needs and culture to family planning service providers.

The Family Planning Initiative was established and developed and the following activities were implemented:

- The Eastern Health Board Community Health Workers completed a family study;
- The CHWs assisted in the facilitation of focus groups;
- Cervical screening was arranged at the Well Women's Centre, Coolock. The CHWs facilitated the arranging of the clinics, transport and appointments for these clinics.

❑ Joint proposal with the Irish Sudden Infant Death Association (ISIDA)

In 1997, the PHC project, in conjunction with the Irish Sudden Infant Death Association submitted a proposal to the Eastern Health Board. Based on the perception that there is a lack of information on risk factors associated with cot deaths, the joint proposal sought to address the specific needs of Travellers in relation to this issue.

The Primary Health Care Project proposed that the project would co-ordinate and manage a Traveller Health Promotion Programme on sudden infant death syndrome for Travellers living in the Finglas/Dunsink area of Community Care Area 6.

The programme would:

- Give information on risk factors and prevention strategies;
- Highlight the changes in lifestyle that would help to reduce risks (e.g. stop smoking in trailers);
- Promote the changes in the environment/lifestyle to prevent cot deaths in the future;
- Develop culturally sensitive and engaging health education materials around the subject of cot death (in consultation with Travellers and the Irish Sudden Infant Death Association).

To date funding of £4000 has been provided for the project out of a total of £17,000 sought. Further support is being sought through the Eastern Health Board Traveller Unit and it is hoped to implement the project as soon as possible.

❑ Eastern Health Board Child Health System (RICHS) : Including a Traveller Dimension

Arising from discussions held under the auspices of the PHC Steering Group, the opportunity was provided to the Project in 1997 to assist the Eastern Health Board in developing an appropriate approach to the inclusion of a Traveller dimension on the Board's computerised child health system (RICHS). Welcoming this development and the fact that it represented the Board's commitment to the targeting of resources on Traveller health, the Pavee Point prepared a response to the Board's

intention to identify Travellers on the system by accommodation status. The response highlighted the following key issues in relation to the effectiveness of the proposed approach:

- Economic status is equally important as accommodation status. While this would normally be assessed on the basis of employment status of parents or educational status, further exploration by the Board and the project would be useful to identify a more creative and appropriate approach for Travellers;
- Some assessment of the stress status generated by living in a hostile society where discrimination is a constant reality would also need to be explored;
- Gender and disability should also be incorporated into the identification system;
- As recommended in the Task Force Report, a strict code of practice including confidentiality, voluntarism and sensitivity should govern the process of Traveller identification;
- Compatibility across Health Boards would be useful in order to develop and improved system of transferring records.

❑ Networking

Networking with other Traveller groups and projects has been a core part of the project actions. The project recognises the importance of networking in order to disseminate and communicate information. Over the duration of the project, the CHWs made contact with and visited many groups around the country. This facilitated the pooling of experiences, skills and resources. It encouraged them, and the groups they visited, to explore different ways of working and to consider the issue of "health" as a priority.

The project has made presentations to the National Traveller Women's Forum, Irish Traveller Movement and to various Traveller events organised by Travellers groups around the country. In addition, the project has participated at national and local levels in a range of activities and events.

❑ Lobbying and Policy Submissions

Advocacy and lobbying are core actions of the PHC project. In order to lobby for the policy changes needed to promote the recognition of the special needs of Travellers and their inclusion in all mainstream provision, a number of submissions to relevant Government policy papers and reports were prepared by the project. One such submission to the Department of Health - when they were working on *'Developing a Policy for Women's Health'* (1995) - highlighted the poor health status of Traveller women in particular and the degree of marginalisation Travellers experience in relation to mainstream services.

Another important contribution of the project to national policy is facilitated through representation by project staff on regional and national committees. Currently, the CHWs act as Traveller representatives on a range of national and regional advisory committees and working groups, including the Eastern Health Board Traveller Unit, the National Health Network and the National Traveller Health Advisory Committee. The PHC project is particularly involved in the latter group which has four representatives from Pavee Point, two directly representing Pavee Point and the other two representing the National Traveller Women's Forum with which Pavee Point have a close involvement. The task of this committee is to draft a National Traveller Health Policy to reflect the analysis of the Task Force on the Travelling Community and to realise it's recommendations. Through its involvement in the Community and Voluntary Pillar in the national partnership arrangements, Pavee Point achieved the inclusion of the statement of commitment to the

implementation of the Traveller health strategy which had been recommended in the Task Force Report (1995).

Another dimension to the policy analysis work of Pavee Point is the tradition within the organisation of developing an informed perspective on issues of relevance to Traveller wellbeing and culture. Using community development-based consultation strategies, the organisation has prepared documents and policy papers as contributions to debate among the wider public at national level. A current example of Pavee Point's work in this area, is the organisation's contribution to the debate on consanguinity - marriage between close cousins / relations - which is an issue of significant importance to the Traveller community. Pavee Point have been working with the PHC project and hospitals to develop a critique on the issue in order to inform national policy. The key perspectives of the organisation were outlined in a discussion paper (Fay, 1996) which included the following points:

- Consanguinity is increasingly on the agenda of Traveller organisations due to its relevance to Traveller health and also due to the more open discussion of the issue as trust has developed between the Traveller community and Traveller organisations.
- In view of the fact that Travellers are seeking information on consanguinity, Traveller organisations have a duty to inform themselves so that they do not give false information and are able to refer Travellers for accurate advice.
- Pavee Point supports the relevant recommendations of the Task Force: *"The Department of Health should commission an in-depth analysis by independent experts of issues related to consanguinity in the Irish context, taking account of the World Health Organisation (WHO) work in this area."* Pavee Point also emphasises that such expertise needs to be deployed in close co-operation with Travellers themselves and Traveller organisations.
- Pavee Point argues that immediate action is required on this recommendation and also on the other related Task Force recommendation that: *"Given that Travellers predominantly marry within their own community, marriage of close relatives is common. Accordingly, a specific, genetic counselling service to Travellers is required to address any risks associated with this."*

❑ National Resourcing Strategy

Besides the support provided by Pavee Point to the PHC project, the organisation has also found itself providing an increasing level of support and technical advice to other projects seeking to replicate the strategy, to health providers at regional and national level, and to the Department of Health. Although this reflects the very positive perceptions of the project's performance both among Traveller development groups and statutory health providers, and the credibility which Pavee Point has built up since setting up the project, the downside is that a significant level of extra work is involved for the project.

Pavee Point staff note that over the past three years, partly as a result of the work of the existing project but also in response to policy developments such as the National Health Strategy and the Task Force on Travelling People, the nature of Pavee Point's work on health and the levels of the work have expanded significantly. However the resources of Pavee Point have not developed apace. To address this issue Pavee Point has successfully negotiated with the Eastern Health Board the appointment of a full-time Health Co-ordinator. The brief of the Co-ordinator will be wide-ranging. It will include general development, monitoring and liaison responsibilities; assisting in the co-ordination of the existing Primary Health Care project in Community Care Area 6 and its

development into the Blanchardstown area; and assisting in the co-ordination of the training and upskilling of existing and new community health workers.
According to Pavee Point's proposal, the approval of this post will enable them to exploit the potential developments in the coming years in the Eastern Health Board area, as well as continue to respond to current work commitments.

Acknowledgement of Impact of the Project

The comments from the project evaluation report (Healy, 1997) noted earlier in this section, provide indications of the success of the PHC project. Discussions with the co-ordination staff, the CHWs and a representative of the Easter Health Board confirm this success. They highlight how the project has made a significant difference to the ease with which many of its target group can now access health service provision, and therefore to the take up of many of the services on offer. In addition the project is unanimously perceived to have facilitated a partnership between Travellers and health board service providers through which information on blockages and barriers has been identified and attitudes have been influenced. With regard to the effectiveness of this partnership, Pavee Point particularly emphasise the role of the Eastern Health Board personnel involved in the project, in making it possible. A key outcome of this development is the representation by the Traveller women on the new Steering Group for the project.

The success of the project has been acknowledged in a number of other ways including the following:

- In 1998 the project received an award from the World Health Organisation;
- In 1998, at the ceremony for presentation of Certificates in Primary Health Care, the project was recommended by the Minister of Health as an effective national model for primary health care delivery for Travellers.

Within this context of positive regard for the project, the following concluding section of this report will provide a brief overview of the main issues arising in relation to the further development of the project and the replication of the project in other areas.

OUTCOMES, LESSONS AND CONCLUSIONS

Outcomes and Plans for Further Development

The Primary Health Care project has now been in operation for over 5 years. As noted in the Annual Report for the first year of the project (1995), the project has broken new ground in terms of:

- Its area of work - primary health care for and by Travellers;
- Its steering group approach - this has involved a successful partnership between a statutory health authority and a non-governmental organisation with widely varying priorities around provision of health services on one hand and Travellers' rights and participation on the other;
- Facilitating the successful involvement of both literate and pre-literate primary health care workers.

As noted by the Eastern Health Board representative, the clearest signal of the project's success is the fact that it is being replicated in other areas.

From the consultations conducted for this current report, a clear consensus is evident among all those involved, that the project has been a success, both in terms of specific outcomes for the Community Care Area 6, in which the project was located, and in terms of the model which has been piloted for the delivery of primary health care to Travellers.

In relation to project outcomes, the following are particularly highlighted:

- The training of a group of 16 Traveller women as community health workers;
- The employment of 16 Travellers in health service provision to their own community;
- A more effective information flow to Travellers about the particular services that are available to them;
- The development of health promotion and educational materials that address the particular needs of Travellers;
- A greater comfort level among the Travellers on the project sites regarding access to and usage of health services and following on from this, a greater take up of services;
- A greater awareness on the part of the Eastern Health Board service field personnel in relation to the culture, beliefs and traditions of Travellers;
- The development of an effective partnership and communication process between statutory health providers with Travellers on the sites and as representatives at national level through Pavee Point;
- The development of an accredited Primary Health Work Training Course, which is based on Pavee Point's developed experience of Traveller Training over 10 years, and also incorporates the experience of Travellers health and education needs which emerged from the PHC project.

Within this context, actions are now underway to further develop the project and also to replicate the model in other areas, both in the Dublin and other health board regions. In relation to development of the Pavee Point project, a number of plans are being finalised. As the project is now being developed to include 6 new sites in the Blanchardstown area, a major focus will be on further skilling the CHWs and linking into special health areas including: child protection, hospitals, consanguinity, alternative treatments, as well as a continued focus on existing areas such as nutrition and dental health. In this way the project will continue to expand the potential scope of

PHC work and thereby role model new areas for other projects and Health Boards. Furthermore, although an engagement with individual casework is not on the agenda of the CHWs' work, which has a more community-based focus, the project will explore the potential for development of training and employment opportunities for Travellers in other health service work: including as social work assistants. In this way the danger of PHC activity being exclusively centred around the work of CHWs will be minimised.

Another focus for the future is the encouragement of greater direct participation of men in the project. Although the project believes that facilitating improved family health, especially for mothers and children, has benefits for men, more direct participation would have been welcomed in line with the community development ethos of PHC actions. The CHWs report that men's involvement is increasing as they are paying more attention to the information being passed on at family level. At the planning stage of the PHC project it had been envisaged that the environmental actions would facilitate the involvement of men but the hold up on these actions prevented this. In the future it is hoped to explore the possibility of such interventions as the testing for testicular cancer.

In relation to the replication of the project in other areas, projects have now been set up in Clondalkin, Tullamore and Dundalk. Planning is underway for projects in Limerick, Galway, Donegal and Kerry. If such development is to be successful, the consultations for this report suggest that consideration must be given to the learning which has emerged from the project over the past five years and key points noted in relation to this learning are briefly discussed below.

Lessons Highlighted By The Project

❑ **Staffing**

PHC projects need sustained staffing and steering group membership. The fact that Health Board staff who left their particular jobs and were no longer available to be involved in the project were not replaced immediately (the time lapse was over a year), had major implications for the project. Furthermore it is vital that the Traveller organisation involved in a PHC project is involved in interviewing any new staff being selected for the project.

❑ **Need for Structured Communications**

Pavee Point argue that there is need for recognition by Health Boards that Traveller organisations can provide a structured communication channel to the Traveller community they represent. This structure can also have a wider remit outside of the project and so can be useful for other purposes e.g. to give feedback to a health board on their services to the Traveller community.

❑ **The Challenge of Mainstreaming and Targeting Services**

The challenge must be acknowledged of how Traveller services can be mainstreamed while at the same time ensuring that specially targeted services are provided to meet special needs Travellers may have which the settled community may not have. For example, Pavee Point recommends the setting up of satellite clinics on sites in order to facilitate Travellers feeling comfortable using the service and so facilitate their take up of mainstream services.

❑ Replication of the PHC project

It is important that replication of the project is not equated with duplication i.e. simply copying the Pavee Point PHC. The project has demonstrated that the PHC model works, but replication of the project must be based on the application of the principles, not the outcomes of the project. Furthermore it must be noted that the PHC project is only one initiative. Other initiatives are needed to properly address the health needs of the Traveller community. In order to ensure that they address priority issues among the Traveller community, these initiatives should come from the Traveller organisations.

❑ Resources

Appropriate resourcing of a PHC project is critical. In line with the Task Force recommendation, this means that Health Boards have a responsibility to ensure the project implementation and development is properly resourced. In addition it means that Traveller organisations need to ensure the adequacy of their resourcing of the project, particularly in terms of their role in pre-training and support for the community workers involved. The extensive capacity building for the CHWs was viewed as a critical factor of the project's success for the PHC. This provided them with the personal skills and confidence base from which they could participate in the special health-focused training. It also equipped them with the critical and analytic skills necessary to identify and articulate the basic health care needs of their community and the responses which they felt could most effectively address these needs. The fact that key elements of the pre-training are the informed insights into Traveller health issues means that Traveller organisations must play a core role in this training.

❑ Partnership

In relation to project planning and management of the PHC, the development of an effective working partnership between Travellers and non-Travellers, voluntary and statutory, was reported to be a slow process involving a lot of give and take on all sides. However, a crucial element consistently emphasised was the willingness to dialogue as equals while respecting each other's roles, responsibilities and ethos. The consultations noted that this was strongly demonstrated at management level where the partnership achieved was perceived to be one where both Health Board personnel and Travellers and Traveller development representatives, recognised and respected the different specialities they all brought to the project. For an effective partnership to develop, it is vital that mutual respect for the different perspectives represented is a core principle of the operation of the group. In relation to the practical area of the day to day project co-ordination, the dual role of the PHN and the Pavee Point development worker, was perceived to be one of the most critical success factors of the project. Through it the project benefited from the experiences and skills which came from the two perspectives of community development for Travellers and Health Board service provision.

❑ Training of Trainers

If the project workers are to be recognised as professional workers, it is important that quality standards are identified and put in place. The project experience suggests that the most effective way to achieve this is to ensure that the workers have standard qualifications and that the training for their qualification is delivered by trainers trained to standard qualifications. In relation to the training of the CHWs: the Primary Health Care Certificate provided the professional training

necessary for new CHWs. Jointly accredited by Trinity College, the Eastern Health Board and Pavee Point, the course development incorporated the original training material and curriculum of the PHC project and equipped the participants with the skills, knowledge and personal development needed for their roles in primary health care service. This course provides the basis for the standardisation and professionalisation of the role of CHWs which is viewed as important if health professionals are to acknowledge and accept their role as health professionals in their own right. The importance the project assigns to ensuring the effective delivery of the CHW role in the replication of the project is reflected in the fact that a proposal was submitted to the Eastern Health Board, for funding to develop a Trainers Training Course in Primary Health Care. This course is being developed by Pavee Point in conjunction with the EHB and TCD. It is envisaged that those reaching the approved standard set by TCD/EHB/Pavee Point would be qualified to deliver and manage a PHC project and also be authorised to act as an extern/peer assessor for other PHC training courses that would be subsequently accredited by TCD.

The Community Health Workers and the Minister for Health, Brian Coven, T.D., the day they received their Primary Health Care Certificates.

Conclusions

In conclusion, it may be noted that the project has been highly successful in establishing Primary Health Care service delivery by Travellers to Travellers in the Eastern Health Board Community Care Area 6 and in demonstrating the value of this approach in other areas. Key steps to be considered by those considering replicating the project are summarised in the box on page 30.

Overall, feedback on the project suggest that it has had positive impact on service take up within the targeted Travellers sites and has also demonstrated a successful model of employment for Travellers interested in health care provision in that sector of the economy known as the social economy. In terms of improving the health of the Traveller community in the area, there is agreement among those involved that significant work remains to be done in view of the low status of Traveller health and the other contextual and environmental issues involved. A consistent conclusion noted in the consultations for this report was that PHC can make an important contribution but given the nature of health problems Travellers face, a variety of responses are needed to the variety of difficulties and problems that Travellers face in the health services. The further development of the project alongside other contextual developments will be needed if the health status of the Traveller community on the project sites is to improve significantly.

Finally, in recording the value of the PHC project, a key dimension emphasised by the Community Health Workers during the consultations for this report is that this project has been a major success in that it presents a vision of what is possible for the next generation of Irish Travellers. The women emphasised their pride in the professional service they are providing to their own community, their satisfaction at their ability (which was validated by the certification they received from the Minister for Health) to have completed the different training modules and imparted the information and encouragement to other Travellers. In addition they expressed the hope that their jobs will be secure so they can get further training and develop even more skills. Most of all however, the women noted their pleasure at the thought of how their role modelling will influence the next generation of Travellers. As one woman said:

> *"My vision is that my grandchildren and great-grand children will have choices. I hope they'll choose education and maybe some of them will be social workers, nurses or even doctors."*

KEY STEPS TO REPLICATION

1. Provide quality pre-training to the potential CHWs. This training should be appropriately paced to meet the special needs of Travellers and should involve sufficient time and resources to enable them to develop the personal and technical skills (confidence, teamwork, communications and analysis) which are core to the preparation for the project implementation.

2. Set up a multi-disciplinary steering group representing the interests of both the statutory health sector and the Traveller community.

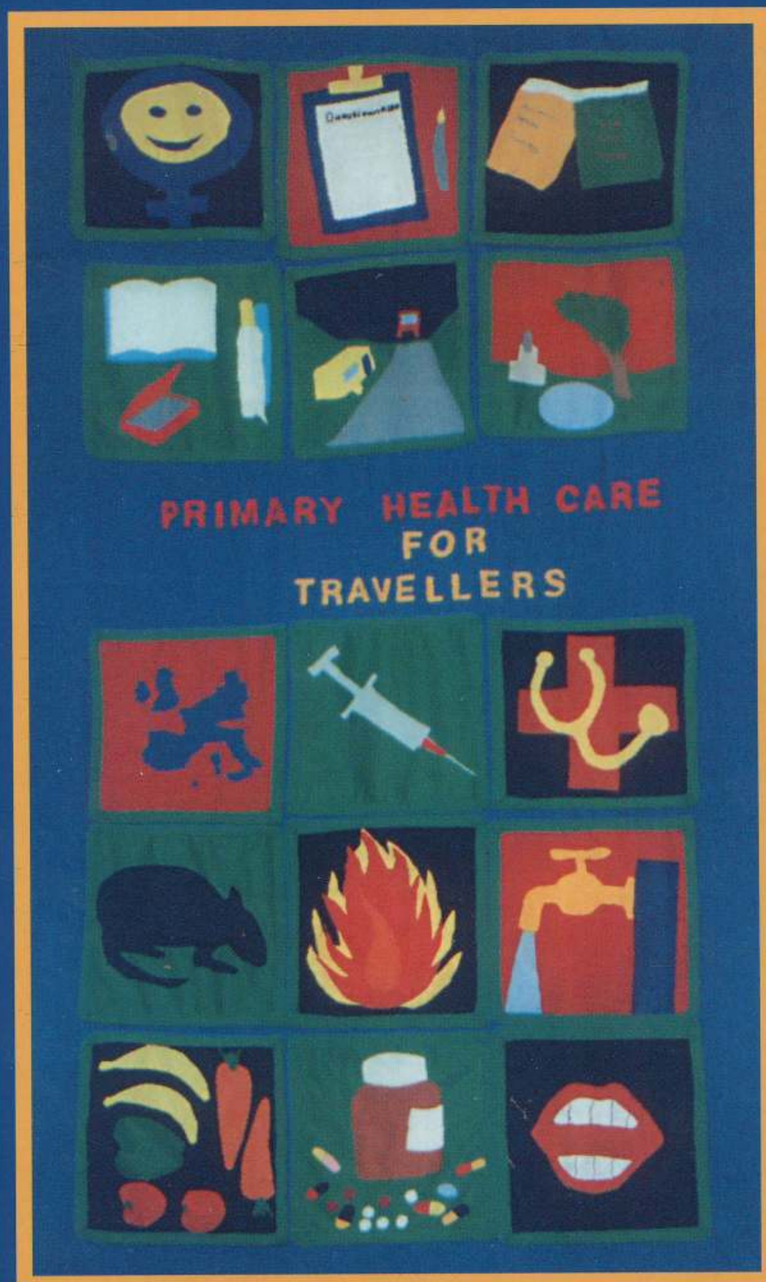
3. Explore the possibility of putting in place arrangements for project co-ordination to be shared between a worker from a Traveller organisation and a professional Health Board worker.

4. Develop a phased work plan for the project actions which includes on-going training for the CHW team.

5. Carry out a base-line survey and involve the CHW team in the design, piloting and implementation of the survey.

6. Develop active networks and linkages with Traveller groups nationally.

7. Document, review and evaluate all project action.



Although not specifically a health education material, an important resource used by the project was a quilt which was prepared by the group in 1995. This quilt represented different aspects of the project i.e. dental, environmental, cures etc. as prioritised by the Community Health Workers. It was used both in Pavee Point as a backdrop to workshops and seminars and also on visits to Traveller Groups. It was a particularly effective information channel on the project to those with poor literacy skills. The quilt was used as the cover page of the first annual report and over the development of the project has come to be a symbol of the project.