

**International Literature and Policy Review on the Links between Poverty and Health, and of Community Development Approaches to Tackling Health Inequalities**

*Draft Report*

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## **Introduction**

This research which was commissioned by the Combat Poverty Agency is concerned with undertaking a comprehensive review of the international research, practice and policy literature on the links between poverty and health and on the role of community development approaches in addressing health inequalities. The research aims of the project include the following:

- To undertake a review of current international literature concerning the relationship between poverty and ill health including the mediators between poverty, community and health.
- To undertake an analysis of existing policy initiatives concerning the promotion of community development approaches in addressing health inequalities.
- To document approaches to implementing community development in the health area including the processes of consultation, collaboration, participation and control of community initiatives.
- To undertake case study investigation of selected community health development initiatives in order to identify characteristics of successful initiatives and examples of good practice.
- To critically examine available research on the impact and effectiveness of community development approaches in reducing health inequalities both in terms of processes and outcomes.
- To make recommendations, based on pertinent policy, research and practice findings, for future strategic development of community development policies and practices in the health inequalities area.

## **Methodology**

The research was conducted using the following methodologies:

- Review of published literature.
- Inventory of unpublished reports and initiatives.
- Case studies of good practice.
- Review of existing policy documents.

## **Review of published literature**

The international literature review accessed through a number of sources:

- The library in NUI Galway contains a number of published books, reports, and journal articles relating to community development and health.
- Reports and literature led by the HRB Unit for Health Status and Health Gain at NUI, Galway were examined.
- Web based searches on community development initiatives and health inequalities e.g. websites for the World Health Organisation, the World Bank, the Irish Government, The NHS, the Community Development and Health Network and others.
- Database searches on Medline, Northern Light, Psyclit, CINAHL, the Cochrane Library and the National Electronic Library for Health etc. Searches were carried out under the headings ‘community development’, ‘health inequalities’, ‘community health’, ‘participation in health’ and ‘community-based health services’.

## **Inventory of Unpublished Reports and Initiatives**

An inventory of ongoing community development initiatives was compiled by surveying key agencies, organisations and individuals known to be active in the area. A copy of the letter and questionnaire employed is attached in the Appendix. Key people were identified through internet based searches and were contacted for information relating to their work such as unpublished evaluation findings and reports.

### **Case Studies of Good Practice**

A number of case studies were chosen to highlight a sample of community health development activity in an international context. The case studies highlight the different issues which community development can seek to address and tackle. The selection criteria included; a clear example of community development approaches being applied, documentation of the project available and evaluation undertaken. The case studies focus on the processes of project development and delivery and the impact and outcome of the programmes.

### **Review of Existing Policy Documents**

The World Health Organisation (WHO) published a report entitled ‘Community Involvement in Health Development: Challenging Health Services’ (1991). The report argues that health will be best served if (1) People from a community – village, neighbourhood, or cultural or socio-economic grouping – take part in planning and implementing their own health care, and (2) health systems are oriented towards preventive and primary rather than curative and speciality health care (Barrett, 1996, p. 73). Inequalities in health have been highlighted all over the world. As a result, health inequalities have been placed on the international political agenda. The research examines existing policy documents relating to health inequalities and highlights that community development is gaining popularity as an effective way of reducing health inequalities. A great number of Irish policy documents identify community development as a means of reducing health inequalities e.g. the National Traveller Health Strategy (2002) states the following:

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

(Dept. of Health and Children, 2002, p.10)

Various policies supporting a community development approach are examined and discussed.

## **Effectiveness and Recommendations for Strategic Action**

The available information on the evaluation of community health development initiatives is examined and key methodological and practice issues are reviewed. The projects selected examine the effectiveness of the process and outcome of community health development initiatives. These projects have sought to tackle health inequalities using community development approaches. The evaluations highlight how the need for the project was identified, the way in which the projects are organised and successes of the projects to date. As a result, it was possible to highlight lessons in best practice and to draw these together when making recommendations for this report.

### **Chapter Outline**

#### Chapter One – The Nature and Extent of Health Inequalities

Chapter one focuses on the concepts of health inequalities and the determinants of health, in particular we consider the effects of community and social capital on the health of individuals within communities. The methods employed to measure health inequalities in society are considered, including income inequality, mortality rates across socio-economic groups, the lifecourse perspective and lay perspectives. The evidence of the extent of health inequalities in Ireland is then presented. International and Irish policy responses to tackling health inequalities are discussed.

#### Chapter Two – Community Development Approaches to Health Inequalities: Policy and Practice

In this chapter the concept of community development and participation in tackling health inequalities are defined. As the effectiveness of community development in tackling health inequalities is dependent upon government commitment and support, we analyse recent international documents, which advocate this approach are analysed. Recent developments in community participation in health care are discussed with regard to developing countries, New Zealand and Britain. From an Irish perspective the NAPS refers to the use of community development approaches to tackle inequalities in health and recent policy documents advocate the use of community consultation and participation in health care. Finally, the application of community development approaches to health care are presented.

### Chapter Three – Case Studies of Community Health Development Projects

This chapter aims to provide a sample of community health development projects currently being delivered on an international level. The case studies selected examine community development activity in a number of countries including: Ireland, U.K, India, New Zealand and Australia. The case studies deal with the following topics: diabetes management, mental health, the Health Action Zones, Primary Health Care for Travellers and community responses to AIDS/HIV. The case studies highlight the wide scope of a community development approach to tackling health inequalities.

### Chapter Four – Evaluating Community Health Development Initiatives

This chapter reviews current research findings on the evaluation of community health development initiatives. The practice implications of the findings are considered and key methodological issues are discussed. Evaluation approaches are examined and the gaps in current findings are considered.

### Chapter Five – Conclusions and Recommendations

This chapter highlights the key conclusions from the review and points to recommendations for future work and research in adopting a community development approach to tackling health inequalities.

## **Chapter 1**

### **The Nature & Extent of Health Inequalities**

#### **Introduction**

In this chapter we focus on the concepts of health inequalities and the determinants of health, in particular we consider the effects of community and social capital on the health of individuals within communities. We then consider the methods employed to measure health inequalities in society including income inequality, mortality rates across socio-economic groups, the lifecourse perspective and lay perspectives. The evidence of the extent of health inequalities in Ireland is then presented, whilst rates of coronary heart disease mortality in the Republic of Ireland are amongst the highest in the developed world and there is relatively lower life expectancy in comparison to other EU countries, little is known about the effects of social variation on ill health. We then focus on international and Irish policy responses to tackling health inequalities.

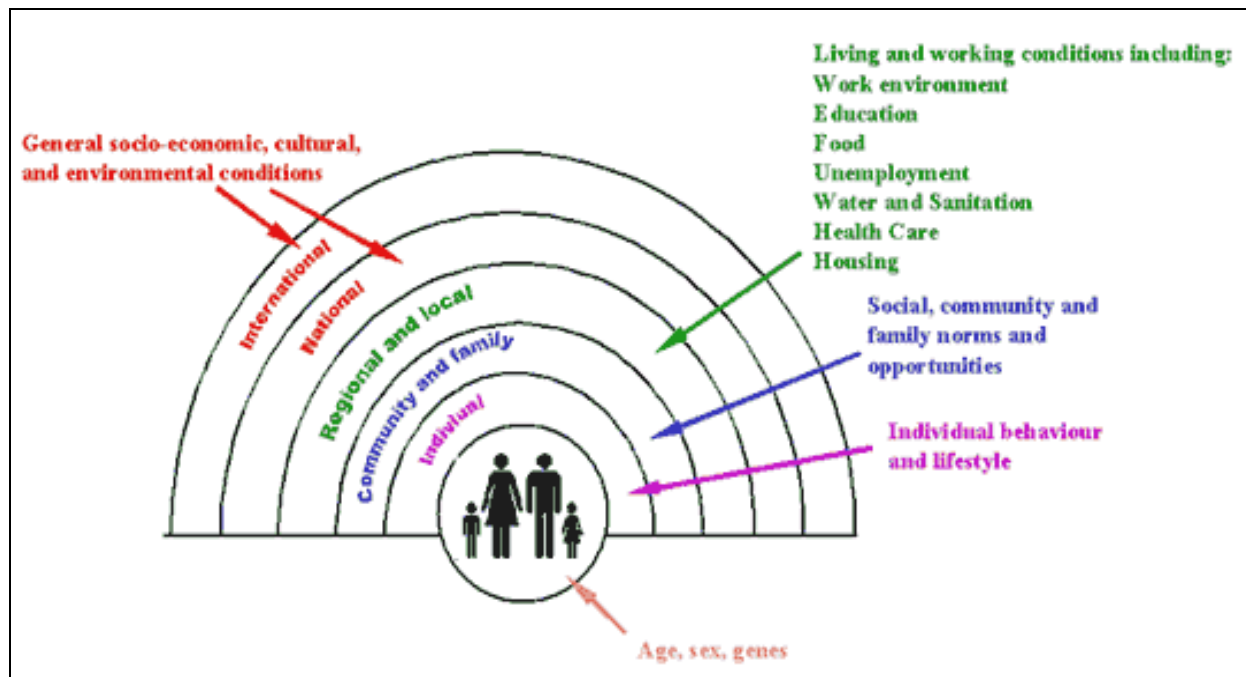
#### **Determinants of Health**

Health inequalities can be defined as “differences in health status which are unnecessary and avoidable and judged to be unjust and unfair” (Whitehead, 1990; 6). International evidence of the extent of health inequalities has been mounting, indicating that gradients exist across social classes to the extent that at any given level on the gradient, individuals have a lower chance of good health than the next level up and conversely a higher chance of good health than the next level down (Whitehead, 1990). It is generally accepted that inequalities in mortality and morbidity stem from differences in location, ethnicity, occupation, income, social class, unemployment, educational achievement and gender and that their existence is unjust.

In order to understand health inequalities we must first consider what factors such as biological, psychological, environmental, lifestyle and health services and how these influence health and well-being. In his annual report of 1999, the Chief Medical Officer states that

“Various definitions of health have been developed over the years that focus on the notion of health as a positive concept rather than merely the absence of disease. Health is now regarded as a resource to be protected and developed so as to enable people to attain their maximum physical and mental capacity” (DHC, 2001; 5).

Figure 1: Social Determinants of Health



Source: North Clondalkin Health Partnership, 2003. Adapted from Dahlgren and Whitehead 1991

Dahlgren and Whitehead (1991) have presented a framework in which to explain the social model of the determinants of health. The model is centred on the individual and their biological factors such as age, gender and hereditary factors which cannot be changed. The most immediate layer of influence on health inequalities are lifestyle and behavioural factors such as diet, smoking, exercise, all of which individuals are supposedly controlled by individual behaviour.

Whilst much of the health promotion strategy in the 1980s targeted these factors by engendering a sense of personal responsibility for maintaining health the contribution of these factors are now considered as being affected by social position, economic resources and the material environment.

Marmot and Shipley (1996) demonstrated clear gradients in mortality across grades of employment amongst English civil servants and argued that one third of the variation was due to differences in risk factors such as exercise, obesity, smoking and blood pressure. Explanations for health inequalities which focus on lifestyle run the risk of ‘victim blaming’ individuals from lower socio-economic groupings for their own unhealthy lifestyle choices. However, there is now greater recognition that the other layers of health determinants affect such health behaviours.

The effects of social and community networks is an area of growing interest for those concerned with understanding the causes of health inequalities. A growing body of research is undertaking to locate individuals within the environments in which they live and explore the contribution of individual behaviors and area influence to health inequalities (for example, Macintyre, Maciver & Soomans, 1993; Soomans & Macintyre, 1995; Cattell, 2001; Popay et. al, 2003). For those such as Graham (1999) there is a belief that the area in which people live exerts an influence on their health, over and above the effects of their individual socio-economic circumstances.

Significant attention is also being placed on the effects of social capital and health and well-being. Lochner, Kawachi and Kennedy (1999) argue that social capital as defined by its principal theorists “ consists of those features of social organisation –such as networks of secondary associations, high levels of inter-personal trust and norms of mutual aid and reciprocity- which act as resources for individuals and facilitate collective action” (1999; 260). Hean, Cowley, Forbes, Griffiths and Maben (2003) explain that social capital is a multi-dimensional concept, “each dimension contributing to meaning of social capital although each alone is not able to capture fully the concept in its entirety” (2003; 1062). They add that the main dimensions of social capital are commonly seen as; trust, rules and norms governing social action, types of social interaction, network resources and other network resources.

In addition, some have begun to consider the antithesis of social capital or social disorganization which McCulloch defines as “the inability of residents of an area to regulate everyday public behaviours and physical conditions within the bounds of their community” (2002). Such disorganization manifests itself in the form of trouble amongst neighbours, the presence of

people lounging on streets and the overall appearance of the neighbourhood would be neglected or rundown. Residential instability, McCulloch argues would also be an indicator of low social capital in an area, this can be measured from census data.

In the context of health inequalities it is argued that social capital as a concept has “added potential for illuminating processes which link determining social structures-like income distribution, policies, local resources- to individual outcomes, and structures to agency, or for clarifying our understanding of health inequalities and the role of place” (Cattell and Herring, 2002; 9). Cattell (2001) in her work explored the dynamics between poverty and exclusion; neighbourhood and health and well-being by considering the role of social networks and social capital. By focusing on specific communities in the East of London, Cattell (2001) deconstructed the complexities of social capital and found that neighbourhood characteristics and perceptions; poverty and social exclusion and social consciousness were the main factors in influencing social capital. Cattell’s research demonstrates that community context is a key feature in understanding the “genesis of social capital. Neighbourhood factors, including the area’s history, work opportunities, local resources and opportunities for participation, played a role” (2001; 1512).

The effects of living and working conditions are clearly outside the individuals’ control and are a product of national and international forces. The extent of their influence can be appreciated in the fact that these factors are frequently used to measure levels of deprivation and inequality particularly at the area or community level. Unemployment has been associated with higher mortality rates, lung cancer, suicide, accidents and heart disease, chronic illness and poorer health in the children and spouses. There is a strong correlation between income distribution and life expectancy, a decline in relative poverty is related to faster improvement in life expectancy. In general terms the lower the level of income, the worse the level of health and for those such as Wilkinson (1996) the relative distribution of wealth in society also impacts on health. Wilkinson argues that the level of income inequality within a society is strongly related to health status and this position has been supported by others studies (Ben Shlomo et al, 1996; Kaplan et al, 1996).

Issues of equal access to health care also constitute an important determinant of health. While broad structural factors in society such as unemployment, poverty and education are implicated in contributing to health inequalities, they are also related to health service provision and crucially access to such services. Whilst there is a distinction to be made between health inequalities and inequalities in healthcare the two are related. The fact that there are two separate waiting lists for hospital care in Ireland, public and private is regarded by many as leading to inequity in healthcare services as access should be on the basis of medical need or capacity to benefit from care and should not be determined by factors such as ability to pay or geographic location (Millar, 2003). However, for those such as Williams the current pre-occupation with issues of equal access to medical care is not the most fruitful approach to correcting problems socio-economic differentials in health outcomes. He concludes “although equality of access is a legitimate and desirable goal, it is likely to play only a limited role in eliminating inequality in health status. Equalisation of preventive care is likely to be the most cost-effective medical approach (Williams, 1990; 95).

### **Measuring Health Inequalities**

International research concerning the differences in mortality rates by socio-economic background and social class emphasize that the more disadvantaged individual circumstances are, the higher the mortality rate relative to the more advantaged individuals in any given society. The level of health inequality in any given country is primarily measured by comparing morbidity and mortality rates against indicators of socio-economic status, usually income, occupation and levels of educational achievement. One of the more conventional methods of measuring levels of health inequality is the analysis of mortality rates by occupation using information from death certificates. This is, however, regarded as a crude measure offering little in terms of explanation for such differences.

Two major investigations into health inequalities in Britain, the Black Report (1980) and the Acheson Report (1998) showed gradients in health according to socio-economic status. The Black Report suggested that social class differences in health were mainly due to material inequality and related social class variation.

The Acheson Report highlighted the role of socially constructed divergence in people's lives and emphasised the need for a multi-sectoral response to tackle health inequalities in the UK (Blane, 1990). Both reports concentrate on the importance early life circumstances have on health in later life and as such recommended the preventing later inequalities in childhood, the need for fairer distribution of resources in society and encouragement of social participation through the provision of educational and employment opportunities.

Graham (2001) argues that there are three main explanations for causation of health inequalities: material, behavioural and psychosocial. Material factors include living conditions, the physical environment, employment conditions and standards of living. Behavioural explanations focus on the individual and their health related behaviours such as diet, smoking alcohol consumption and exercise. Psychosocial factors involve the psychological effects of living in an "unequal society. For example, perceiving oneself to be worse off relative to others may carry a health penalty, in terms of increased stress and risk-taking behaviour" (Graham, 2001; 15). In reality, it is the combination of these factors that or the sum of all parts that result in health inequalities as "the distinction between behavioural and materialist explanations is seen as increasingly artificial (O'Shea and Kelleher, 2001; 292).

Recently, research has been focusing on factors operating across the lifecourse of individuals. As Graham explains the lifecourse perspective is occupying an increasingly important place in public health research and policy as it "builds an appreciation of time, and of individual lifetimes in particular, into explanations of health inequalities" (2001; 75). The lifecourse perspective holds that inequalities in the structure of society shapes life chances do that advantages and disadvantages cluster cross-sectionally and accumulate longitudinally. In turn observed social class differences in health in old age can be seen as the "biological correlates of socially structured, differential exposure to health hazards" (Berney et al, 2001; 79). Thus the focus for the lifecourse perspective researchers is on the effect childhood circumstances have on health in later life.

Berney et al (2001) argue that the most powerful research tool for this type of study is what is known as a birth cohort study that is a longitudinal study which tracks its subjects from birth throughout life. Ireland is currently conducting its first birth cohort study the 'Lifeways Study' being conducted by the Research Unit on Health Status and Health Gain, NUI, Galway. 1,064 mothers have been recruited in Dublin and Galway and cross-generational data is being gathered with baseline information being obtained regarding the mother, child, fathers, grandparents and siblings. The research involves clinical information and health lifestyle information regarding the project participants over a five year period.

Whilst considerable progress has been made in research activities concerning the measurement and explanation of health inequalities, as Blaxter (1997) notes, how people themselves think about inequalities in health is rarely investigated. Advocates of lay consultation, such as Popay et al. (1998) and Blaxter (1997, 2002) argue that investigations relating to individuals' perceptions of health may be the missing link leading to a deeper understanding of health inequalities. Lay health beliefs are those views held by members of society who are not health professionals and it could be argued that lay consultation may enable us to gain some understanding of the complex myriad of factors involved in health inequalities. The plethora of debates surrounding the causes and consequences of health inequalities in modern society rarely consult the 'experts', those who know first hand what it is that causes ill-health in their own lives and inequalities in the context of the wider society they inhabit.

Popay and Williams (1996) identify three dimensions of lay expert knowledge relevant to the area of public health research and practice; lay understandings of the relationship between individual behaviour and life circumstances, lay theories about aetiology and the predictive power of lay knowledge. Pill and Stott (1985) contend that individuals are more articulate discussing their own illness as opposed to illness in general and that it is possible for people to attribute different causes of illness depending on what it is they are discussing. Blaxter's (1997) review of lay attitudes to health revealed ironically that those most vulnerable to disadvantaged circumstances were more likely to believe that social inequality in health does not exist.

The Voices of the Poor study was based in the Poverty Reduction Group of the World Bank and was led by Deepa Narayan. This work resulted in a three-part series (Can Anyone hear Us?; Crying Out for Change; From Many Lands) publication entitled Voices of the Poor which gathers the views of over 60,000 poor men and women from sixty countries around the world. The work was undertaken to inform the World Development Report 2000/2001: Attacking Poverty.

The study, which employs participatory and qualitative research methods, marks a change from other large-scale poverty studies, which are largely quantitative in nature. The study presents the realities of poor people's lives and explores four main themes; how poor people view poverty and wellbeing, problems and priorities, experiences with institutions of the state, markets and civil society and the nature of gender relations.

The study presents the perspectives of poor people, in their own voices, from around the globe. These perspectives are used as a basis for sketching out a vision of development that focuses on five areas of action to empower poor people to move out of poverty and to reorient states to become more effective agents of poverty reduction. The five actions include; 1) promote pro-economic policies; 2) invest in poor people's assets and capabilities; 3) support partnerships with poor people; 4) address gender in equity and children's vulnerability and 5) protect poor people's rights. The study highlights that the perspectives of poor people point out some clear directions and strategies and that solutions have to be locally owned and adapted.

It would appear from the literature that community participation and consultation has a diverse range of applications both in terms of the type of community settings in which they have been developed i.e. geographic communities such as the Health Action Zones and communities of interest such as HIV, mental health and first time mothers. Whilst the impetus and motivation behind these projects and initiatives have all varied they have one common foundation and that is a concern with redressing health inequalities by what Billings terms "facilitating a collective response to community defined health needs, and enabling disadvantaged groups to have an effective voice in policy decisions that affect their health and well-being" (2001; 472).

Currently in Ireland, a study is being conducted which explores the perceptions of individuals and communities on the nature, extent and causes of health inequalities and their views on the policy strategies for tackling identified inequalities.

This study forms part of a wider five-year programme of work, funded by the Health Research Board, which is being carried out at the Unit for Health Status and Health Gain at NUI, Galway. This component of the study is concerned with; how individuals and communities can give voice to their health needs, the barriers individuals experience in achieving positive health and quality of life, the first hand experiences of the barriers individuals in the community encounter when accessing health services, and the view of the community on how their health can be improved. The study is adopting a community based approach by centering the study on two communities in Ireland, one Urban the other Rural, one on the West Coast of Ireland the other on the East. Recent research indicates that the area in which people live exerts an influence on their health, over and above the effects of their individual socio-economic circumstances. (Miller & Barry et al 2003)

### **Ireland and Health Inequalities**

Whilst such disparities in health have been extensively investigated in other countries little is known about the effect of socio economic background and health in Ireland. What we do know, however, is that individuals living in poverty in Ireland experience cumulative disadvantage including poor housing conditions, lack of income, low educational attainment level amongst other factors. Whilst there remains a notable lack of research about poverty and its impact on health in Ireland we can ascertain that poverty is widely accepted as risk factor for health.

As Benzeval and Judge explain;

“It has been recognised that poverty is associated with poor health ... some people may have poor health because of low income while others have a low income because of prior sickness”

Thus the question remains as to whether poverty causes ill health or ill health causes poverty. As Burke (2001) reveals while there is a lack of evidence in Ireland to “demonstrate a direct chain of causation between ill health and poverty” there is a growing responsiveness to the damaging impact of ill health and disability on inclusiveness in society.

However, as O’Shea and Kelleher (2001) explain “the relationship between economic status and health accordingly works in both directions”. Callan et al (1999) contend that individuals

in Ireland with a disability or illness have a 56% risk of falling below the 50% income poverty line. This link between ill health and poverty has recently been acknowledged by the Government

“Apart from unemployment, illness is one of the major contributory factors to poverty. In the case of serious illness, a person’s ability to maximise his or her employment opportunities and to be financially independent can be severely affected. In less severe cases, the significant cost of obtaining treatment for illness can reduce the standard of living in a household.” (Cited in Burke, 2001).

Moreover given the recent emphasis in the health inequality literature on the Life course perspective toward health inequalities, the current level of childhood poverty in Ireland gives much cause for concern. Benzeval et al. (2001) report on numerous studies conducted in the U.K which asserts that economic hardship in childhood results in a greater chance of ill health in adulthood. Their analysis highlights the ‘enduring importance’ of childhood poverty for health damaging consequences of low-income adulthood. A recent Irish study concluded that those on low incomes are more likely to experience ill-health and their children are exposed to greater health risks (McKeown and Sweeney, 2001; 17).

“Inequalities in health status between socio-economic groups have been demonstrated in this country and are persisting. The factors involved in the relationship between ill health and socio-economic background are very complex and hard to unravel” (Chief Medical Officer Report, Dept of Health and Children, 2000; 30).

The majority of investigations into disparities in mortality utilise income as a predictor of outcome, as Irish census data does not record income, analysis into health inequalities tend to be driven by social class. Hence, what we do know about poverty and health inequalities in Ireland is based on the indirect measure of social class or socio-economic variations in health. Whilst rates of coronary heart disease mortality in the Republic of Ireland are amongst the highest in the developed world and there is relatively lower life expectancy in comparison to other EU countries little is known about the effects of social variation on ill health (Kelleher et al, 2002; 36).

Nolan's (1990) seminal study of male mortality rates in Ireland by social class was based on 1981 population and mortality data of males aged 15-64. Nolan found substantial differences in mortality across social groups and he concluded that in Ireland poor people are more likely to experience ill health and die younger. O'Shea (1997) took Nolan's analysis a step further by considering male mortality differentials by socio-economic groups between 1986-1991. O'Shea's results showed significant variation in standard mortality rates by socio-economic groups, in particular a sharp class gradient associated with diseases of the circulatory system.

In 2001, the first report on all-Ireland mortality since the early 1920's was produced. This report by the Institute for Public Health lays bare for the first time evidence of health inequalities assumed to be there by many. The study looked at death rates for specific causes of mortality by social class in both the Republic and Northern Ireland. In both jurisdictions members of the lowest socio-economic group were 100 per cent more likely to die of cancer than higher socio-economic groups, 120 per cent more likely to suffer heart attacks and strokes and 200 per cent more susceptible to disease of the lung and other respiratory disease.

Irish health and lifestyle surveys show that medical card holders generally report lower levels of health and quality of life than non-medical card holders. The SLAN (the survey of lifestyles, attitudes and nutrition) survey conducted at NUI, Galway (Friel et al, 1999) found that those who hold medical cards consistently do worse than non-GMS patients in every parameter measured, from health care need and utilisation through to smoking and drinking patterns.

Self-rated health is regarded as a powerful proxy for morbidity and mortality. As Kelleher et al (2003) make clear GMS eligibility is an important predictor for self-rated health and "in many ways it is the most robust measure of actual income available, since it is rigorously means tested".

The Chief Medical Officer, Dr. Jim Kiely highlighted the existence of health inequalities in Ireland in his annual report of 1999 (Department of Health, 2000). In this report Dr. Kiely analysed poorer health and earlier death rates amongst individuals in the lower socio-economic

groups in Ireland. The report emphasised that the identification and understanding of the determining factors in health inequality, together with the development of strategies are “arguably the most pressing priorities facing us in the health field”. Dr. Kiely concluded that ‘inadequate medical care’ was a contributory factor to such inequalities ‘there is evidence that the less well off in society have poorer access to health services’ (Department of Health, 2000).

Indeed, much of what we know in Ireland concerning health inequalities focuses on men. In terms of documenting health inequalities amongst women in Ireland the area is problematic. Conlon (1999) in her investigation concluded that the only available regular indicators of morbidity in Ireland are indirect and relate to health service utilisation rates. Thus, data collection in relation to morbidity in Ireland is underdeveloped when compared to morbidity indicators which are standard in other health administrations (1999, VI). Classification by occupation on death certificates is one of the more popular methods of collating mortality rates in Ireland. However, classification regarding women has been omitted in many studies as they have been classified according to their husband’s occupation. Indeed, O’Connor (1998) argues that roughly three-fifths of Irish married women still return their main occupations as ‘housewife’. This approach has meant that whilst information is available for men there is no such measures for women.

### **International Policy Responses to Health Inequalities**

Leon, Walt and Gilson (2001) argue that there is currently a wave of international and national interest in tackling health inequalities and poverty. They explain that whilst not all governments perceive inequalities in wealth and health to be something the public sector can or should address, all governments are interested in improving economic growth. As such the WHO argues that health is the key to reducing poverty and promoting development. Leon, Walt and Gilson observe that health inequalities and inequities within countries are not understood in the same way throughout the world.

For example, in countries such as the United Kingdom, Sweden and the Netherlands, the majority of health inequality research has focused on the mechanisms that generate socio-economic gradients in ill-health and mortality.

Thus from this perspective as health inequalities are mainly a function of the aetiology of disease policy solutions centre on primary prevention. In contrast, low and middle income countries researchers regard the problem as creating policies to ensure more equitable provision of health care. The contrast inherent in these policy solutions to tackling health inequalities lies in the fact that in many high income countries access to health services is relatively universal whereas in developing countries “the issue of organising and funding the health services has been more central to inequalities in health” (Leon, Walt and Gilson, 2001; 592). The issues highlighted by Leon, Walt and Gilson reflect the complexity of the policy issues inherent in addressing poverty, inequality and health emphasising the importance of both prevention and access to health services.

Within the EU a group of researchers are working in conjunction with the European office of the WHO to build on the European countries monitoring programmes of health inequalities. *‘The European Network on Interventions and Policies to reduce Socio-economic Inequalities’* have conducted a review of policy interventions that are likely to reduce health inequalities in Europe.

The work is built on previous studies which demonstrate that while the northern European countries with established welfare states have lower absolute differences between different social classes in health status and life expectancy, the relative social gradients are just as marked in the north as the south of Europe. However there were no clear recommendation made by the group as to which policies would be most effective in tackling health inequalities.

In response to the prevalence of inequalities in health in Europe, the European Science Foundation (ESF) has established an interdisciplinary programme *‘Social Variations in Health Expectancy in Europe’*. The programme has reported a stepwise increase of the risks of ill-health and premature death with decreasing socio-economic standing in all European countries and as such a reduction in inequalities in health is now a priority for several European governments.

The impetus for the programme stems from the fact that although there has been substantial progress in the field of inequality in health, the research base is still inadequate and this hampers effective policy making as there is insufficient evidence. The ESF programme once completed should produce a significant scientific understanding of health inequalities in Europe which will in turn enable the development of evidence based health policy.

The work of the ESF group to date reports that cross-national comparative analyses on socio-economic differences in mortality in Europe show a consistent pattern of a stepwise increased risk relating to lower educational and occupational standing. Social differences in mortality were found to be particularly large in France and Finland and the social gradient was steepest in the age group 30-64 years, and it was more pronounced in men than women. The group also report that the underlying causes of mortality in the northern and southern European countries: social gradients of mortality in the northern countries are most evident for cardiovascular in particular coronary heart diseases, whereas in the southern countries, neoplasms show the most consistent pattern of socio-economic differences (ESF, 2000).

In the UK, the Independent Inquiry into Health (Acheson Report) 1998 was welcomed for its acknowledgement of not only the impact of health inequality but the evidence it presented to highlight how such inequality can be reversed by redistributive social policy centered on a multi-sector response (Blane, 1999). In addition, the report recommends that all government agencies engage in Health Impact Assessment which implies that “all policies likely to have a direct or indirect effect on health should be evaluated in terms of their impact on health inequalities, and should be formulated in such a way that by favouring the less well off they will, wherever possible, reduce such inequalities”.

However, for some the weakness in the Acheson Report lies in the fact that it made thirty-nine recommendations and failed to prioritise any of them. As Davey-Smith et al argue that “the format of the recommendations is more like that of a shopping list than of health strategy” (1998; 1465). The arguments put forward to defend such criticism include the failure to present the recommendations in a hierarchy and the key fact that inequality in health follows closely on

inequalities in wealth, the vagueness of the recommendations and that fact that they were not costed thereby making it impossible to engage in cost benefit analysis (Davey-Smith et al, 1998).

In addition, the Labour government in the UK established a Cross Cutting Review ‘Tackling Health Inequalities’ (2002). The review highlights the importance of local community involvement in action to tackle health inequalities, if interventions are to have a long-term and sustainable impact (2002; 2). Furthermore it pinpoints key areas for intervention in tackling health inequalities by employing a multi-sectoral approach to breaking the cycle of inequalities, tackling the major killers, improving access to public services and facilities and strengthening disadvantage communities. Figure 2 provides a summary of the key areas for intervention.

Judge and Paterson (2001) note the more elaborate approach to health inequalities targets adopted by Sweden ‘*Health on equal terms – national targets for the population’s health*’ explicitly recognises the social determinants of health inequalities and as such sets targets for reductions in exposure to the social determinants of disease and injury. Judge and Paterson note that the Swedish strategy “is the most comprehensive strategy for reducing health inequalities yet.

**Table 2 Summary of Key Areas for Intervention Cross Cutting Review: Tackling Health Inequalities**

**Infant Mortality**

- Building on Sure Start
- Reducing smoking in pregnancy
- Reducing teenage pregnancy and tackling its causes and effects
- Improving housing conditions for children in disadvantaged areas
- Other forms of early intervention in the NHS

**Life Expectancy**

- Reducing smoking in the manual groups
- Improving prevention services and control of other risk factors in primary care
- Promoting environmental improvements (e.g. housing)
- Targeting the over 50s

**Breaking the Cycle**

- Promoting healthy pregnancy
- Targeting early years development
- Narrowing the gap in educational attainment
- Reducing teenage pregnancy, and tackling its causes and effects to reduce the risk of social exclusion for teenage parents and their children.

**Tackling the Major Killers**

- Reducing smoking in manual groups and those groups with the highest incidence
- Improving prevention and treatment services, including NHS implementation of National Service Frameworks
- Improving nutrition, particularly amongst children and reducing the prevalence of overweight and obesity.
- Increasing levels of physical activity amongst deprived groups
- Narrowing the gap between social classes in accidental injuries amongst children.

**Improving access to Public Services and Facilities**

- Improving mainstream services to reflect need
- Improving access to, and quality of, primary care in disadvantaged areas
- Improving public transport in disadvantaged areas and for disadvantaged groups
- Using technology and information to improve access

**Supporting Specific Groups**

- Improving health services for specific groups with poor health outcomes
- Improving housing for older people and families with children on low incomes
- Reducing accidents and ending fuel poverty among older people and families with young children
- Enabling disabled people to return to work
- Addressing the health needs of prisoners and homeless people.

Source: Cross-Cutting Review (2001)

Not only does it give explicit recognition to the multiple social determinants of health, but sets goals for the psychosocial conditions as well as for its health service (2001; 53).

The strategy proposes 17 health (see Figure 3) policy goals to be achieved by 2010, grouped into the following six areas:

- Strengthening social capital
- Growing up in a satisfactory environment
- Improving conditions at work
- Creating a satisfactory physical environment
- Stimulating health-promoting life habits
- Developing a satisfactory infrastructure for health issues. (cited in Judge & Paterson, 2001; 51).

Figure 3: Goals and Targets to reduce health inequalities in Sweden by 2010

<p><i>A strong sense of solidarity and feeling of community in society</i></p> <ul style="list-style-type: none"><li>• Reduced poverty</li><li>• Reduced segregation in housing</li><li>• Compensatory resources for children and young people in socially disadvantaged housing areas</li></ul> <p><i>A supportive social environment for the individual</i></p> <ul style="list-style-type: none"><li>• Reduced isolation, loneliness and insecurity</li><li>• Increased participation in leisure and cultural activities</li></ul> <p><i>Safe and equal conditions in childhood for all children</i></p> <ul style="list-style-type: none"><li>• A secure bond between children and their parents</li><li>• A nursery and school system which promotes health by strengthening pupils' self confidence and achievements at school</li><li>• Improved mental health amongst children and young people</li></ul> <p><i>A high level of employment</i></p> <ul style="list-style-type: none"><li>• Opportunity for life long learning</li><li>• Low unemployment</li><li>• No discrimination against immigrants or the disabled in the labour market.</li></ul> <p><i>A healthy working environment</i></p> <ul style="list-style-type: none"><li>• Adaption of the physical and mental demands of work to meet the requirements of the individual</li><li>• Increased influence and opportunities for development at work</li><li>• Reduced overtime</li></ul>
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*Accessible green areas for recreation*

- Quite and safe green areas near residential housing
- Stimulating playgrounds at nurseries and schools
- Good outdoor facilities near sheltered housing for the elderly and disabled

*A healthy indoor and outdoor environment*

- Reduce exposure to passive smoking
- Well ventilated indoor environment
- A high standard of building, protection from radiation, fresh air and non-toxic environment in accordance with the proposals of the Environmental Targets Committee

*Safe environment and products*

- A safe home environment, a safe traffic environment and safety in other public places
- Reduced use of products hazardous to health and those causing allergies.

*More physical exercise*

- More physical exercise at school and in connection with work
- More physical exercise in people's leisure time

*Healthy eating habits*

- Increase consumption of fruits and vegetables and reduced consumption of fat and sugar
- Reduced number of overweight people in society
- Increased number of women breastfeeding

*Safe and Confident sexuality*

- Reduced spread of sexually transmitted disease
- Reduced number of unwanted pregnancies
- No one should be discriminated against because of their sexual orientation.

*Reduced Tobacco Consumption*

- A tobacco free start in life from the year 2010
- A halving up to the year 2010 of the number of people under the age of 18 who take up smoking
- A halving up to the year 2010 of the number of smokers amongst those groups in society who smoke the most
- No one should be subjected against his will to smoking by those around him

*Reduced harmful alcohol consumption*

- Reduced total consumption
- Total abstinence in connection with pregnancy, driving and sailing, at work or when undertaking a sporting activity
- Reduced occurrence of drinking to a state of total inebriation

*A drugs free society*

- Reduced access to drugs
- Reduced number of young people trying and using drugs

*A more healthy orientated health service*

- More effective measures for the prevention of ill health and for health promotion on an individual, group and community level
- Increased co-ordination to insure equal development of health in the population
- Advanced methods and strategies for work on preventing illness and promoting health

*A co-ordinated effort on public health*

- Responsibility for health planning in the hands of district councils and county councils
- Development of co-ordinated sector strategies within the field of public health on a national level by the responsible authorities
- A co-ordination of public health issues in the Cabinet Office and the Ministries
- A regular up-date regarding national policy for public health presented to the Swedish parliament.

*Long term investment in research, method development and education*

- Intensified research into the value, costs and effects of various interventions
- Improved methods for managing work on public health
- Increased investment in education in the discipline of public health

Source: National Committee for Public Health, Sweden (2001) cited in Judge & Paterson (2001; 54-5).

### **Policy Responses to Health Inequalities in Ireland**

The problem of health inequalities in Ireland is recognised in the National Anti Poverty Strategy (NAPS) published in 1997. NAPS evolved from the Governments pledge in 1995 to develop such a strategy at the UN world summit in Copenhagen. This ten year plan aims to reduce poverty in Ireland by prioritising the areas of income adequacy, educational disadvantage, unemployment, urban poverty and rural poverty. Whilst no specific targets for a reduction in health inequalities are contained in the NAPS, it does compel all government departments to consider poverty reduction in their decision-making and strategic planning and to conduct ‘poverty-proofing’ of all policies introduced. In a review and updating of the NAPS targets the government states that its overall objective is to reduce the inequalities that exist by making health and health inequalities central to public policy and thereby proposing a mutli-sectoral approach to alleviating health inequalities. The key target in this area is to reduce the gap in premature mortality between the lowest and highest socio-economic groups by at least 10 per cent for circulatory diseases, cancers and injuries and poisoning by 2007 (Dept of Taoiseach, 2002; 12).

Under the Programme for Prosperity and Fairness (PPF), NAPS was updated and targets were established in the area of health. The main objectives of the social partners in terms of health care are

- To improve the health status of the population, capitalising on the significant expansion of health service resources in recent years.

- To improve access to quality health care services in order to strength social inclusion and cohesion and also to monitor socio-economic health inequalities.
- To promote models of primary/Community health care.
- To promote general health and well-being through strengthened health promotion policies, research and the creation of a supportive environment, with particular emphasis on at risk groups as indicated in lifestyle surveys or named in NAPS.
- To improve the effectiveness of the health service, using the significant increases planned in health spending. (Government of Ireland, 2000; 93)

In terms of implementing these objectives the Government proposes action in the areas of implementation of the health strategies, improved health infrastructure, review of bed capacity in hospitals, health promotion programmes, an examination of the medical card scheme, improved services for drug misusers, a reform of mental health legislation and improved services for people with disabilities (Government of Ireland, 2000; 93-94).

As part of the review of NAPS, a NAPS and Health Working Group was established to develop health targets and an associated implementation and monitoring framework. The targets proposed by the Working Group were selected with aim of reducing the gap in health between rich and poor, promoting equity of access to health services and developing new ways of working to address the main factors which link poverty and ill health. The group noted that the process was constrained by a lack of information and the need to develop better information systems has been built into the targets. The targets are centred on health status, equity of access, impact of public policy on health targets and the monitoring and revision of targets.

These targets are presented in Figure 4.

- **Figure 4: NAPS and Health Working Group Health Targets**
- The gap in premature mortality between the lowest and highest socio-economic groups should be reduced by at least 10% for circulatory diseases, for cancers, for injuries and poisoning by 2007.
- The gap in life expectancy between the Travelling Community and the whole population should be reduced by at least 10% by 2007.
- The life expectancy and health status of Travellers, asylum seekers and refugees should be monitored so that targets can be set for asylum seekers and refugees and reviewed and revised for Travellers, by 2003.
- The gap in low birth weight rates between children from the lowest and highest socio-economic groups should be reduced by 10% from the current level by 2007.
- There should be increased equity of access to effective primary health care services by 2007.
- There should be increased equity of access to public acute hospital services by 2007.
- There should be equitable access to available effective interventions for cardiovascular disease and cancers by 2007.
- There should be increased equity of access to community supports for continuing care by 2007.
- A comprehensive injury prevention strategy to reduce higher injury rates in people at risk (children, young men and older people in lower social economic groups) should be developed by 2003.
- The income threshold in the guidelines for the medical card should be increased with a view to removing impediments to access to health services and taking particular account of the needs of children.
- An equality dimension should be integrated into the delivery and development of health and personal social services by 2007.
- It should be government policy for all relevant sectors to recognise and accept their responsibility for health by developing multisectoral working and the adoption of Health Impact Assessment by 2007.
- Systems to monitor NAPS health targets and indicators should be included within the National Health Information Strategy.
- A programme of research should be set up to support the development of further NAPS health targets and indicators.
- Adequately resourced and supported systems should be put in place to ensure that NAPS health targets and implementation strategies are reviewed and revised (2001; 5-8).

The current health strategy '*Quality and Fairness*' (Department of Health and Children, 2001) asserts that inequalities in health can exist for reasons such as geographical location, gender, age, ethnicity, hereditary factors and socio-economic status. In addition, the strategy acknowledges that poverty, unemployment, education, access to health services and environmental factors all play important roles in determining the health of individuals. The strategy points to the evidence of the ESRI, Institute of Public Health and the Health and Lifestyle Surveys amongst others to demonstrate clear occupational class gradients in mortality and conclude that there is a strong relationship between health and socio-economic status in Ireland. The strategy aims to tackle such inequality by utilising a multi-sectoral approach.

More specifically, Objective 3 of the strategy is that 'health inequalities are reduced'. In order to achieve this objective the strategy sets out a number of key actions. The strategy pledges that a number of programme of actions will be implemented to achieve NAPS health targets for reducing health inequalities. It sets out the following targets to eliminate the impact of deprivation and disadvantage;

- The gap in premature mortality between the lowest and highest socio-economic groups should be reduced by at least 10 per cent for circulatory diseases, cancers, injuries and poisoning by 2007.
- The gap in life expectancy between the Travelling Community and the whole population should be reduced by at least 10 per cent by 2007.
- The life expectancy and health status of Travellers should be monitored so that by 2003, the existing targets can be reviewed and revised.
- By 2007, the gap in birth weight rates between children from the lowest and highest socio-economic groups should be reduced by 10 per cent from the current level.

It is envisaged that these targets will be met through increased equity in access to a number of key health services, increasing the income threshold in the medical card guidelines and the development of a multi-sectoral approach to health and health impact assessment.

The strategy also aims to take initiative to eliminate barriers for disadvantaged groups to achieve healthier lifestyles. This will be done by implementing existing policy on health promotion activities, identifying barriers to the adoption of health lifestyles by those on a low income and developing effective intervention programmes to overcome such barriers and developing initiatives to assess the health needs of the communities and then developing prevention/education programmes to sustain local community support. Action is also to be taken in improving the health of Travellers, homeless people, refugees and asylum seekers, drug misusers and prisoners.

In February 2003, the Government and Social Partners published a new national agreement 'Sustaining Progress' in which builds on the commitment made under PPF to reduce health inequalities. The agreement concurs with the premise within the National Health Strategy

*'Quality and Fairness'* that Primary Care has a central role to play in the delivery of health and personal services and that the Government is committed, within resource constraints, to advancing the implementation of the primary care strategy. Whilst the document focuses on change in the area of the structure of the health services, rehabilitation facilities, information systems, health promotion and education and eligibility, it pays particular emphasis to Health Impact Assessment, again reinforcing a multi-sectoral approach to tackling health inequalities. The agreement defines Health Impact Assessment as:

“a process which takes social determinants of health into account, will be developed so that relevant policies, strategies and legislation undergo a comprehensive process of health proofing so that their impact on the physical, mental and social well-being of the population is positive” (Government of Ireland, 2003; 59).

## **Conclusions**

Whitehead claims that the “accumulating evidence demonstrates that the size of social differentials in health varies over time, and in different countries” which point to the conclusion that “the observed health inequalities are not inevitable” (1998; 5). Rather Whitehead points to the fact that many of the underlying factors determining health can be influenced by social policy. Thus policy responses to health inequalities focus on a multi-sectoral approach to tackling inequality with consultation of local communities in identifying health needs. Recent Irish policy documents and strategies highlight a commitment to tackling health inequalities by utilising a multi-sectoral approach to achieve the main target of narrowing the gap within socio-economic health inequalities.

Whilst the Irish government is clearly committed to tackling health inequalities in Ireland the implementation of these policies is as yet to be completed or evaluated. At present a question mark looms over the future of the health strategy, as many of its own deadlines have failed to be met (Millar, 2003). The ability of the current strategy to effectively tackle health inequalities may be determined by finances as opposed to the ability of policy makers to effectively implement the strategy. However, for the first time in Ireland there is evidence of a multi-sectoral approach and clear government commitment to narrowing the gap in mortality rates

amongst socio-economic groups. In Chapter two we will consider the role of community development in tackling health inequalities and the policies both international and national, which support this move.

## **Chapter 2**

### **Community Development Approaches to Health Inequalities: Policy and Practice**

#### **Introduction**

In this chapter we will define and explain the concept of community development and participation in tackling health inequalities. As Tones and Tilford argue “a healthy nation is not only one which has an equitable distribution of resources but one which also has an active empowered community which is vigorously involved in creating the conditions necessary for healthy people” (2001; 26). As the effectiveness of community development in tackling health inequalities is dependent upon government commitment and support, we analyse recent international documents which advocate this approach. Recent developments in community participation in health care are discussed with regard to developing countries, New Zealand and Britain. From an Irish perspective the NAPS refers to the use of community development approaches to tackle inequalities in health and recent policy documents advocates the use of community consultation and participation in health care. Finally, we consider the application of community development approaches to health care.

#### **Community Development and Health**

Community development is a concept that currently has widespread appeal in public health policy. As a public health practice community development has been defined as; “the process of organising and/or supporting community groups in identifying their health issues, planning and acting upon their strategies for social action/change, and gaining increased self-reliance and decision-making power as a result of their activities” (Labonté, 1993, p.237). This appeal has strengthened since the release of the 1986 Ottawa Charter which placed importance on the participation of communities in defining and developing solutions to their own health problems. A community development approach to tackling health inequalities recognises the socio-economic influences on health and in addition, that the context in which people live directly influences health status (Laphorne, 1996).

Community development is a process by which a community is enabled to define its needs and is supported to develop the confidence and resources to take action to address them. It is a process, which embraces the concept of involvement, commitment, citizenship, participation and partnership. It involves people gaining an understanding of, and control over, the social, economic and political forces affecting their lives. Effective community development work can build individual confidence and organisational capacity in communities and this can complement other policy initiatives to achieve a better quality of life, and more effective solutions to problems in communities ([www.scdc.org.uk](http://www.scdc.org.uk)).

Lindsey et al argues that four important aspects of a community development approach are;

- Citizen action,
- Voluntary participation, co-operation and collaborative problem solving,
- Empowerment and
- A focus on holistic, community wide outcomes.

As such they argue that community development is viewed as a “philosophical orientation or process of engagement within the community, rather than as a method to which community members must adhere” (Lindsey et al, 2001; 829). The principle of participation, central to community-based approaches to health, is based on the premise that change is more likely to occur when the people it affects are involved in the change process. Participation by local people is posited as having the greatest and most sustainable impact in solving local problems and in setting local norms. The process of participation and engagement is recognised as promoting a sense of ownership of the programme and enhancing overall community competence and capacity (Wallerstein, 1990; Robertson and Minkler, 1994). Rifkin et al. (1988) define community participation as “a social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, take decisions and establish mechanisms to meet these needs”. A number of related constructs also appear in the literature including community ‘involvement’, engagement ‘empowerment’, ‘ownership’, ‘competence’ and ‘capacity’ building (Wallerstein and Bernstein, 1994).

“The fundamental premise is that when people are given the opportunity to work out their own problems, they find solutions that have a more lasting effect than when they are not involved in such problem solving. Changes that take place within a community are considered peripheral to the changes that take place within people themselves” (Lindsey et al, 2001; 829).

Community participation in health care is regarded as an essential component of the wider strategy for primary health care which has gained global acceptance in the wake of the WHO ‘Health for all by the year 2000’ strategy. Zakus defines community participation in health as process by which members of the community, either individually or collectively:

- Develop the capability to assume greater responsibility for determining and assessing their own health needs and problems;
- Plan and decide on solutions;
- Become actively engaged in implementing the solution;
- Create and maintain organisations in support of these efforts; and evaluate the effects and bring about necessary adjustment in goals, targets and programmes on an ongoing basis (Zakus, 1998; 481).

Community participation in health can take many forms one of which is the community development model. As Robinson and Elliott argue despite a vast and growing literature around community development and health there appears to be no agreed definition of the concept and that confusion has arisen ‘from overlapping meanings and the interchangeable use of terminology’ (2000; 221). In this context the authors present the following definitions of community development and its variants;

- *Community development*: The process, by which a community identifies its needs, develops an agenda with goals and objectives, then builds the capacity to plan and tack action to address these needs and enhance community well-being.
- *Community organisation*: the process of involving and mobilizing major agencies, institutions and groups in a community to work together to coordinate services and create programs for the united purpose of improving the health of a community.

- *Community based*: the process of agency development of solutions for health problems which incorporate community consultation and input thus allowing adaptation of the implementation to suit local needs/ circumstances (Robinson & Elliott, 2000; 221)

Community development health projects employ a community development approach to improving the health and well-being of people within a defined community. These projects may be initiated by local people themselves or they may be stimulated through the activities of health-related professionals. However, what differentiates a community development approach in health from others is the following:

- The importance of a broad-based definition of health; where good health is not merely the absence of disease but includes physical, mental and social well-being.
- The need for participation and collective working. Often this involves forming partnerships with others, crossing professional boundaries and working with people who are often excluded from participating in and/or influencing mainstream activities.
- That those within the community, the users of health services, should determine their own mandate. When necessary, this involves challenging and seeking to influence statutory services.
- The need to reduce inequalities in health, which derive from a range of socio-economic factors and unequal access to health care information and services. (Community Health UK, 2002; 1)

The Sheffield Health Authority uses the following definition of community development, specifically as it relates to health:

“Community Development in health aims to enable the active involvement of people, especially those most oppressed and marginalised, in issues, decision-making and organisations which affect their health and lives in general. It can take place at the grass roots, in neighbourhoods or communities of interest and also at an organisational level in policy, planning and service delivery. It is based upon people identifying their own needs and how these can best be met. It involves enabling people to come together to share experience,

knowledge and skill; to support their participation and encourage their involvement in influencing policy making and service development on issues which concern them.

Integral to the Community Development approach is a commitment to equal opportunities and confronting inequality and discrimination. A Community Development approach to health emphasises the holistic nature of health, and a positive approach to health, well-being and its promotion” (cited in Smithies and Webster, 1998).

In terms of the ability of community development to tackle health inequalities Burton and Harrison (1996) state that “the community development approach to health is positive and proactive and can enable people who do not normally access existing services to access them. As it seeks to redress the balance and to help communities help themselves it can begin to reduce inequalities in health and ensure that those with the greatest need have the best care” (1996; 31). The issue of health inequalities, partnership working and consultation are all key components of community development health projects. Many projects have been working to reduce health inequalities through partnerships and consultation for a number of years e.g. Community Action on Health in Newcastle Upon-Tyne and so in this respect may be regarded as being ahead of government thinking.

The importance of helping people regain control over their lives and involving them in planning is recognised as valuable (Laughlin and Black, 1987). A community development approach recognises the socio-economic influences on health and also recognises that the context in which people live directly influences health status and affects the way decisions are made regarding health (Black, 1980, Whitehead, 1987). As Cox and Findlay (1990) note “the process of involvement and participation which is fundamental to community development is itself health promoting, enhances self-confidence and helps people to feel more in control of their lives” (Cited in Burton and Harrison, 1996, p. 31)

### **The Policy Context: International**

Community involvement in health care remains one of the key elements of the primary health care (PHC) model endorsed by the Alma Ata Declaration of 1978. This policy was adopted by all member states of the WHO and remains a key component of contemporary health policy internationally.

The rationale behind community participation as put forward by the Alma Ata Declaration is:

- Health services are misused or under-utilised if community people are not involved in the development of these services.
- Communities do have materials, manpower and money that they will contribute to health improvements provided they are involved in decisions about these improvements.
- Improvements in health status today depend more on what people do and for themselves rather than new discoveries in science and technology.
- Individuals and communities have the right and duty to be involved in decisions that affect their daily lives (Rifkin and Ong, 2000; 66).

The Alma Ata Declaration made several important assertions; it declared that the existence of gross inequalities between advantaged and disadvantaged individuals was ‘politically, socially and economically’ unacceptable and the individuals not only have a right but a duty to participate individually and collectively in the planning and implementation of their health care (Tones and Tilford, 2001; 21). The major focus of the Ottawa Charter (WHO, 1986) was for social change and political activity, calling for the following five strategies to be implemented; the need to ‘build healthy public policy, create supportive environments, strengthen community action, develop personal skills and reorient health services. Following a conference on health promotion held in Jakarta, the WHO Jakarta Declaration 1997, the five strategies of Ottawa were reaffirmed and in addition participation and community involvement were also endorsed. This marked a paradigm shift in the ethos of health promotion activities. In the past much health promotion activity centred on individual and lifestyle behaviour however following the Ottawa Charter the focus was on strengthening community action.

The WHO in a report entitled 'Community Involvement in Health Development: Challenging Health Services' (1991) argues that health will be best served if

- People from a community – village, neighbourhood, or cultural or socio-economic grouping – take part in planning and implementing their own health care, and
- Health systems are oriented towards preventive and primary rather than curative and speciality health care (Barrett, 1996; 73).

The PHC movement recognises that health is not determined simply by the provision of health services, but is also a function of development. In order to undertake PHC, one must take into account the environmental and social conditions that influence health. PHC should be envisaged not simply as a service delivery agenda, but rather as an inter sectoral, multilevel process of social and economic change (Li et. al, 2001; 281). PHC is a flexible approach, it can be adopted to the specific needs and culture of a community. The process of PHC values empowerment, partnership and advocacy. Therefore, community participation and partnership are key requisites for the success of PHC.

In 'Health For All in the 21<sup>st</sup> Century' the WHO presents the findings of three evaluations of the 'Health For All' strategy which demonstrate that whilst progress had been made a number of significant barriers to progress existed in many countries including:

- Insufficient political commitment to the implementation of HFA;
- Failure to achieve equity in access to all PHC elements;
- The continuing low status of women;
- Slow socio-economic development;
- Difficulty in achieving inter-sectoral action for health;
- Unbalanced distribution of, and weak support for, human resources;
- Widespread inadequacy of health promotion activities;
- Weak health information systems and no baseline data;
- Pollution, poor food safety and lack of safe water supply and sanitation;
- Rapid demographic and epidemiological changes;

- Inappropriate use of, and allocation of resources for, high cost technology;
- Natural and man made disasters (WHO, 1998; 6).

The WHO argue that the inequities and increasing gaps between rich and poor in many countries and communities, even as economic growth continues, threatens social cohesion and in several countries contributes to violence and psychosocial stress (1998; 9). In terms of achieving 'Health for All' a key aspect is the strengthening of the participation of people and communities in decision-making and action for health which is a central tenet of the PHC approach.

By creating 'partnerships for health' the WHO advocate that governments should aim to create an environment that stimulates and facilitates both formal partnership and community based informal networks (1998; 44).

### **Policy Context: Developing Countries**

Community participation, involvement and development in health have been extensively employed in low income countries. Barrett in his analysis of the application of the Alma Ata principle of community participation in health care notes that in Central America much of past and contemporary health care policy can be related to government priorities. For example, Costa Rica's rural health system which developed during the 1970s stopped short of attaining the WHO ideal model when it abandoned a far-reaching program in community participation in 1982 as it threatened invested interests at both the national and local level and because such levels of activism lead to a fear of socialism amongst the elite. In Nicaragua, health care development in the early 1980s should record levels of community participation but stagnated under the pressure of armed attacks and economic disintegration. In El Salvador, the civil war placed pressures on those who would participate in community development but eventually this led to a society in which community development could become highly organized. Barrett notes that in the 1990s integrated, participatory, community-level health systems in Central America are few and far between in explaining this he concludes that "the major roadblocks to community health lies in the policies and priorities of national governments and the elite economic and military fractions they serve" (Barrett, 1996; 80).

Zakus in his analysis of Mexico's primary health care system observes that implementation and institutionalization of community participation in Third World countries is usually regarded as necessary not merely because of a commitment to 'Health For All' but "to make up for the lack of government and other private resources within the health sector" (1998; 475). Zakus centers his study on a community initiative in state of Oaxaca, in Mexico where the Ministry of Health in response to federal directives created a programme of community participation as one of its major public health delivery strategies. At the heart of this strategy was a commitment to active participation of communities in various aspects of the delivery of their local health services.

In practice, Zakus observed that this involved the co-option of community members as 'volunteer auxiliaries' to provide and perform health related services on behalf of the Ministry for a 'meager monthly monetary incentive'. These community health workers were central to the programme as they were the ones who actually delivered the health service to the community and thereby extended health coverage to many under serviced parts of the population. Zakus found that it was not the communities that were organizing themselves in an organic manner to participate in the provision of their own health services;

"Rather, it was the Ministry which actively co-opted them into their policy and strategy of expanding the health services ... the Ministry clearly used its resources and influence to co-opt community members to stimulate community participation at the local level" (1998; 489)

The auxiliaries and health committees at the local level were under resourced, not given adequate training and preparation and were very much left to their own devices to develop and implement activities and yet much of the organisation and structure of the 'community participation' was determined and imposed by the Ministry of Health. Jewkes notes that some commentators would argue that it was due to the need to generate extra resources for health that community participation was identified as having great potential in developing countries. Whilst in both developed and developing countries others have argued that community participation makes and health promotion and health services more effective (1998; 845-6).

## **The Policy Context: New Zealand and Britain**

The department of Public Health at the University of Otago in New Zealand produced a report 'Social Inequalities in Health: New Zealand 1999' for the Ministry of Health. In the foreword to the report the Director-General of the Ministry of Health notes that in all age, gender and ethnic groups, people living in more deprived neighbourhoods have shorter life expectancy, higher rates of hospitalisation, and greater exposure to tobacco smoke than those living in less deprived areas.

In terms of policy responses to this community difference in health inequalities the Director General concludes that;

“This evidence supports the view that policies need to target communities as well as families and individuals. This conclusion is further reinforced by the analysis of income inequality at the health locality level, which indicates that communities with more unequal income distributions pay a price for this inequality in health terms” (cited in Judge & Paterson, 2001; 4)

In Britain recent health policy and reports endorse the view that community based initiatives can address health needs and improve health and well-being. And that community development is an appropriate way to tackle the consequences of long-term disadvantage. Recommendations from the Acheson Report (1998) espouse the importance of community based interventions. The Acheson Report contains a number of elements, which are conducive to implementing community approaches to health inequalities. These include the following:

- The adoption of the socio-economic model of health is significant in relation to community participation as participatory approaches to health improvement are more in key with materialist/structural explanations of health inequalities.
- Many of the recommended interventions are aimed at the social and community level rather than the individual level.
- The report calls for a need to increase equity in the health service; community participation is one way to achieve this.

- The report draws on the concept of social capital, with a stress on the importance of social cohesion in combating the effects of poverty and social exclusion. This also bodes well for community participation. (Lewando-Hundt, 2000; . 6)

Since taking power in 1997 the New Labour government has attempted to create a ‘Third Way’ in social and welfare policy which attempts to create a middle ground between the traditional ideologies of the right and left “Towards a politics of pluralism which aims to encapsulate both the state and the market, the public and the private, to forge pragmatic solutions for the construction of social democratic societies” (Crawshaw and Simpson, 2002; 2.1).

Two of the guiding principles of the ‘Third Way’ are the desire for ‘a strong civil society with strong communities’ and ‘modern government based on partnership and decentralisation’ (Hill, 2000; 63). These principles have been operationalised in a series of community based social policy initiatives known as Comprehensive Community Initiatives (CCI’s) which have a long history in the US. The CCI’s in Britain such as the Health Action Zones (HAZ) and Education Actions Zones are what Crawshaw and Simpson describe as “complex partnership programmes designed to bring together service providers in the public, private and voluntary sectors to work towards ambitious targets of area improvement by reducing inequalities in health and education” (2001; 4.2). These programmes operate on the underlying assumption that the devolution of authority and responsibility to the community level is a necessary aspect of this process.

Initiatives such as the Health Action Zones and Sure Start concentrate on the socially excluded and are based on the premise of the community development orientation of empowerment and partnership (Billings, 2000; 473). The Health Action Zones (HAZs) were the first area-based initiative to be established by the New Labour government. The establishment of HAZs in deprived areas in England reflect the government’s commitment to tackle health inequalities. HAZs were established as part of the policy drive to tackle health inequalities and improve the health of the population. They work on a number of issues including recent government priorities such as cancer and mental health. HAZs are also addressing teenage pregnancy, smoking, drugs and targeting population groups such as minority ethnic communities, children and older people. The policy context of the HAZ is displayed in Figure 1. In the time since the

HAZs have begun, they have achieved a number of successes. The HAZs will be discussed in

**Figure 1: The current policy context for HAZs**

**Saving Lives: Our Healthier Nation:** White paper (1999) set out a programme to save lives, promote healthier living and reduce health inequalities. It outlines the requirements for local targets to be met through strategies and initiatives such as the HAZ as well as emphasising the importance of partnership.

In the **NHS Plan (2000)** the government gave a commitment that local targets for reducing health inequalities would be reinforced by the creation of national targets.

**National Health Inequalities Targets** were announced by Alan Milburn in February 2001:

- Starting with children under one year, by 2010 to reduce by at least 10% the gap in mortality between manual groups and the population as a whole.
- Starting with health authorities, by 2010 to reduce by at least 10% the gap between the fifth of areas with lowest life expectancy at birth and the population as a whole.

**Tackling Health Inequalities: Consultation on a plan for delivery.** In August 2001, the government launched a cross-government and cross sector consultation on the action needed to deliver the national health inequalities targets. HAZs strongly welcomed this consultation and the opportunity it provided to share local learning on tackling inequalities.

The **NHS Plan (2000)** sets out the government's vision for reform in the years to come, it focuses largely on service issues (as well as making reference to health inequalities, health determinants and public health issues). It also stresses the need to work in partnership with other departments and agencies to tackle the underlying causes of ill-health.

**Shifting the Balance of Power within the NHS** published in 2001 sets out in more detail the significant organisational changes that will be required for modernisation.

It proposed abolishing the executive regional offices of the NHS and two thirds of health authorities creating new primary care trusts (PCTs) to take on a raft of responsibilities from health authorities:

- Strategic Health Authorities (approx. 30) will replace the existing 95 health authorities. They will monitor the performance of local health services and provide a link with the Department of Health.
- PCTs will be responsible for identifying and commissioning the health services needed by local people. By 2004 they will be responsible for allocating 75% of the NHS budget of £57bn.
- The 8 DH regional offices are to be abolished and replaced with 4 regional directors of health and social care.

The **NHS Plan** specifically pledges that the NHS will play a key part in the implementation of the Strategy for Neighbourhood Renewal.

**A New Commitment to Neighbourhood Renewal:** A National Strategy launched in January 2001 sets out the government's vision for narrowing the gap between deprived neighbourhoods and the rest of the country. At national level the Action Plan will be implemented by the new Neighbourhood Renewal Unit (NRU).

**New Deal for Communities** is a programme that forms an integral component of the National Strategy for Neighbourhood Renewal. It aims to regenerate some of the country's most deprived neighbourhoods through an investment of around £800m over the next 10 years.

**Local Strategic Partnerships** are the key dynamic in implementing the neighbourhood renewal strategy at the local level bringing together public, private and voluntary sector providers with the community and business sectors, and offer the opportunity to rationalise the many partnerships that already exist.

- Under the NHS plan, the NHS will help to deliver LSPs into which (the learning from) HAZ could be integrated to strengthen the links between health, education, employment and other sources of social exclusion.
- Post April 2002 PCTs will be expected to take the lead role for health for instance in ensuring alignment between Health Improvement and Modernisation Plans (HIMPs), PCTs plans, Community Strategies and Neighbourhood Renewal Strategies.

**Health Improvement and Modernisation Plans (HIMPs)** replaced Health Improvement Programmes in 2001. They have a similar remit but with the addition of incorporating modernisation into the planning process. The HIMP Development Group has been assigned the task of ensuring that HIMPs are well placed to implement the NHS plan and can underpin some of the work of the LSPs.

Single integrated Public Health Groups across regional offices (ROs) and government offices (GOs) for the regions will enable regeneration to embrace health. The co-location of residual functions of the ROs and GOs will also support this.

Source: Cross-Cutting Review (2001; 17-18).

further detail in Chapter Three.

The Health Living Centre (HLC) Initiative was launched in January 1999 with the aim of promoting good health, targeting disadvantaged areas and groups and reducing inequalities in health. As with the HAZ initiative, HLCs aim to address the wider determinants of health and contribute to reducing inequalities. HLCs will also develop services aimed at reducing smoking, improving physical activity and dietary advice, and provide health information and advice to people. A key element of the HLCs is that they involve the local community in the planning of the projects. This is done in partnership with a wide range of organisations from the health and local authority sectors, and voluntary and community groups. HLCs also provide support in the implementation of national and local health strategies.

The British Cross Cutting Review ‘Tackling Health Inequalities’ (2002) highlights the importance of local community involvement in action to tackle health inequalities, if interventions are to have a long-term and sustainable impact (2002; 2). Particularly with regard to strengthening disadvantaged communities in which multiple deprivation and the links between areas based deprivation and health inequalities are strong. “Evidence of effective interventions to improve health particularly among the most disadvantaged, shows the importance of building partnerships and developing community based approaches” (Cross Cutting Review, 2002; 8). In its analysis of successful interventions to tackle health inequalities the review identified the following key findings on successful interventions:

- Local assessment of needs, especially involving local people in the research process itself,
- Mechanisms which enable organisations to work together- ensuring dialogue, contact and commitment.
- Representation of local people within planning and management arrangements – the greater the level of involvement the larger the impact.
- Design of specific initiatives with target groups to ensure that they are acceptable (i.e. culturally and educationally appropriate), and that they work through settings that are accessible and appropriate.

- Training and support for volunteers, peer educators and local networks, thus ensuring maximum benefit from community-based initiatives.
- Visibility of political support and commitment.
- Re-orientation of resource allocation to enable systematic investment in community-based programmes.
- Policy development and implementation that brings about wider changes in organisational priorities and policies, driven by community based approaches.
- Increased flexibility of organisations, so supporting increased delegation and a more responsive approach. (2002; 62).

### **The Policy Context: Ireland**

In order to facilitate an examination of the potential of community development to tackle health inequalities and alleviate poverty we must contextualise community development within the Irish policy environment. In Ireland, the introduction of the NAPS, PPF, Sustaining Progress and the current health care strategy we can observe explicit reference to issues such as partnership, community participation, and the role of community development projects in delivering health care to target groups. Furthermore, there appears to be a new impetus to tackle health inequalities using a multi-sectoral approach in Ireland as discussed in Chapter one. The section of the chapter will review the main recommendations and targets of current Irish public policy in relation to community involvement, participation and consultation in the health domain.

The current health strategy (discussed in detail in chapter one) *'Quality and Fairness'* is committed to developing initiatives to assess the health needs of the communities and then developing prevention/education programmes to sustain local community support. The Chief Medical Officer in his 2001 annual report highlights the Health Strategy's commitment to people centeredness as one of its key principles. Explaining that this principle sets out a commitment to increased involvement of consumers as partners in planning and evaluation as an important component of achieving full health potential, addressing health inequalities and promoting openness and accountability (Chief Medical Officer, 2002, p. 40). Community Participation is

seen as an essential component of a more responsive and appropriate system of care, which is truly people-centred. The report defines Community participation as:

“A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change” (Chief Medical Officer, 2001; 40)

The Primary Care Strategy ‘*Primary Care: A New Direction*’ (2001) recommends that mechanisms be put in place in order to ensure that there is active community involvement in primary care teams. Encouraging and facilitating the involvement of local community and voluntary groups in the planning and delivery of primary care services will strengthen community participation in primary care.

Primary care teams will be encouraged to ensure user participation in service planning and delivery. Consumers will have an input to needs assessment initiated by the Health Boards. A greater input from the community and voluntary sector will enhance the advocacy role of primary care teams in ensuring that local and national social and environmental health issues, which influence health, are identified and addressed (Dept. of Health and Children, 2001; 39).

In relation to health, NAPS aims to bring about a reduction in poverty and inequalities in health. Community development has been identified as an effective approach for supporting people and their health needs. Community development leads to more appropriate responses to health needs within a certain community or area. Whilst the original NAPS document (1997) outlined health issues no specific targets were set. However, in the context of the NAPS target of improving the lives of people living in disadvantaged and urban and rural areas, community development is regarded as a key strategy in achieving this;

“A key element in the rejuvenation of local communities is the mobilisation of those communities and the involvement of those affected by poverty and social exclusion in the process of regeneration. In this regard local community projects, women’s groups, community arts projects, community based youth projects and community education projects have an important role to play ... the Combat Poverty Agency will continue to develop its support services to local voluntary and community groups tackling poverty”

(1997; 17-18). In addition, NAPS endorses a partnership approach to tackling inequalities acknowledging as it does the importance of consultation with and involvement of the voluntary and community sector, users of services and those with first hand experience of poverty (1997; 21).

Under the PPF, NAPS was reviewed and new targets were set in health (discussed in chapter one) by the Working Group on NAPS and Health underlying the work of this group is a number of key principles guiding the group which they propose should be an important consideration in the adoption of the health targets, the associated implementation strategy, monitoring framework and review process. One of these key principles is community development which the Working Group state is “about people working collectively for social change which will improve the quality of their lives, the communities in which they live or the society of which they are part. It is about enabling and empowering those who are disadvantaged to identify and articulate need, to participate in working for change and to influence decision-making structures that affect them, their communities and wider society. It is an essential mechanism for supporting peoples and communities health. It must be committed to and resourced at national, regional and local level” (2001; 16-17).

The National Health Promotion Strategy 2000 – 2005 refers to the Healthy Cities Initiative as an important vehicle for enhancing citizen involvement in the decision-making process. It states that the community as a setting has the potential to reach individuals or population groups who may not be associated with other settings e.g. older people and the Travelling Community (Dept. of Health & Children, 2000; 49). The Strategy supports the development and implementation of a community development approach. It argues that such an approach is important so that;

“People can gain greater controls over their lives, have greater access to information, and develop supportive relationships and skills in decision making and the ability to access resources. The challenge for Health promotion is to work with communities and not for communities” (Dept. of Health & Children, 2000; 49)

The Strategy has the following objectives;

- To appoint a National Community Co-ordinator to support the development and implementation of community-based health promotion initiatives.
- To work in partnership with relevant bodies to develop a health village/town model.
- To adapt and develop community-based programmes to meet the needs of groups within the population.
- To evaluate community-based programmes to determine their effectiveness.
- To identify and report on evidence based community approaches including partnership models.
- To establish pilot projects with a view to identifying models of good practice that provides a holistic approach to health within disadvantaged areas. (Dept. of Health & Children, 2000; 49)

As discussed in chapter one the current and future National Agreements, the PPF and 'Sustaining Progress' include health inequalities objectives within their framework for social inclusion and equality. The PPF also makes a commitment to support voluntary effort and participation in Irish society, in particular it aims to:

- To enhance the quality of life for citizens and civil society by promoting, encouraging and sustaining all forms of voluntarism and participation.
- To promote the participation of people from low income groups and young people in representative democratic processes.
- To enhance the capacity of communities experiencing disadvantage (whether geographical or sectoral) to articulate their collective interests and to participate in community activity, in partnership with public authorities.
- To develop training and support mechanisms so that individuals, communities and organisations can develop a self-sustaining ethos grounded in volunteering and can engage with their communities and civil society as a whole.

- To support the community and voluntary sector and be informed by its views and experiences when formulating and devising strategies to tackle disadvantage, exclusion and poverty (Government of Ireland, 2000; 92).

It is clear, therefore, that the government is committed to community participation, consultation and activism in partnership with voluntary organisations and public authorities in order to enhance the quality of life for citizens. *'Sustaining Progress'* refers to the importance of community participation in the context of the Primary Care Strategy stating that learning from that process will be used to inform models of participation appropriate to the Health Strategy. Furthermore, there is a commitment to developing health promotion and education activities in partnership with the community, targeting specific areas such as smoking, healthy eating, substance abuse, sexual health and other lifestyle changes (Government of Ireland, 2003; 58-59).

### **Community Development Approaches to Health in Ireland**

A questionnaire was designed with the aim of examining community development and health activity in Ireland. A number of projects were sent a letter outlining the nature of the research with a questionnaire attached<sup>1</sup>. The key findings are highlighted in a table in the appendices. The following examples presented in the tables are not representative but illustrate examples of successful community development health initiatives currently being implemented in Ireland. They simply provide a snapshot of community development approaches to health currently being delivered in Ireland.

#### **Pavee Point - Dublin**

The Publication of 'The Traveller Health Status Study' (Barry et. al., 1986) gave rise to considerable concern about the health status of the Travelling community in Ireland. This report was significant because for the first time comprehensive data regarding the health status of the Travelling community was made available and it confirmed perceptions that many Travellers experience ill-health.

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<sup>1</sup> See appendices for a copy of the letter and questionnaire.

Pavee Point identified Primary Health Care (PHC) as an effective community-based approach to tackling the health inequalities experienced by the Travelling community. Quirke outlines the following key features of PHC provision:

- Community participation is at the heart of sustained 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 into 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.

(Pavee Point, 2000, p.2)

The PHC programme for Travellers emerged out of training under the New Opportunities Programme supported by FÁS. The training enabled the Traveller women to identify areas for further training. The Traveller women identified the need to develop skills and knowledge relating to their own health needs and the needs of their own community. As a result, Pavee Point submitted a proposal to the Eastern Health board for the establishment of a PHC training programme for Travellers. The catchment area of Community Care Area Six was proposed due to the fact that a number of the women were residents in the area and that over 250 families lived in the area representing a population of over 2,000 Travellers (Pavee Point, 2000). The programme officially began in 1994. It 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 in accessing health services (Pavee, 2000).

The Eastern Health Board and management in Pavee Point hold overall responsibility for the programme. Together they appointed a steering group, which consists of the following:

- Two Eastern Health Board representatives
- Two Pavee Point representatives (PHC Co-ordinator and Director of Pavee Point)
- Two Traveller women (one permanent and one rotating)
- A technical advisor (Trinity College Dublin)

The steering group oversee the implementation of the programme. The programme is co-ordinated by a community worker and a public health nurse. The programme aims to train Traveller women to become Community Health Workers (CHWs) in their own communities.

The role of the CHWs is as follows:

- To access and disseminate health information to the Traveller community and contribute to the promotion of health
- To increase Traveller participation in health issues and develop an advocacy role in their community.
- 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.
- To contribute to a response to policy initiatives which impact on Traveller health status.
- To contribute to the development of health education materials appropriate to the Traveller community.
- To take positive action to ensure the specific health needs of Traveller women are addressed.
- To liaise and work with other relevant statutory and voluntary organisations as appropriate.
- To be responsible and accountable to the co-ordinators of the programme.

(Pavee Point, 2000, p. 11)

The programme is evaluated on an ongoing basis. An external evaluator carries out the evaluation while the project is also evaluated regularly by the co-ordinators of the programme. Part of the evaluation involved carrying out a baseline Traveller health survey to identify the needs of the Traveller community in the programme catchment area. To date, the programme has been a success. A number of Traveller women have been trained as CHWs. There is a more effective information flow to Travellers about health services. Health promotion poster and leaflets have been designed targeting the Travelling community. The programme has led to the development of a successful partnership between statutory health providers and Pavee Point. The PHC programme has been replicated in a number of other areas around Ireland.

### **Belfast Healthy Cities - Belfast**

The aim of Belfast Healthy Cities is to make Belfast a more healthy and decent place to live in, by working with planners and policy-makers to make health a central consideration on all policy development. Belfast Healthy Cities also seek to:

- Build capacity to promote action to tackle inequalities in health.
- Support communities to assess health impact at the local level
- Promote information and stimulate debate on public health issues within the city.

Belfast Healthy Cities programmes are concerned with health development, including policy work and healthy urban planning; equity in health and Community Health Impact Assessment. The programmes are based on requirements established by the European Network but have been developed in partnership with the people of Belfast to ensure that they are suited to local needs. It is aimed to highlight the key factors associated with each of the programmes. They are as follows:

Community Health Impact Assessment – The aim of Community Health Impact Assessment (CHIA) is to enable community organisations to actively participate in assessing policy planning, predict how these plans will impact on the health of local communities, and make recommendations how to minimise negative effects.

The approach is a new way of looking at the impact of policies, programmes and projects and is strongly supported by WHO and the government in Northern Ireland. The overall aim is that health impacts will become a consideration in all planning and decision-making processes. The CHIA programme aims to develop tools to be used by community and statutory agencies at local level and also to build an information and support network, and develop collaboration between local communities and statutory organisations. Statutory groups and staff in community projects will be trained in order to enable them to carry out HIA on their own work. The results from the CHIA are due for publication in 2004.

Health Development – The Health Development programme pulls together a number of different elements of the work of Belfast Healthy Cities, including city health development planning; advocating that health issues be placed policy makers agendas and working to integrate health and sustainability issues into urban planning processes.

Inequalities in Health – Belfast Healthy Cities programme ‘Equity in Health – Tackling Inequalities’ aims to assist statutory, voluntary and community organisations in promoting action to tackle inequalities in health. The programme is currently ongoing and involves a number of training days, each focusing on a different topic. The results of the programme will be disseminated once available.

Belfast Healthy Cities receives core funding from the Eastern Health and Social Services Board and Belfast City Council. In addition, they are supported by the Belfast Regeneration Office; Northern Ireland Housing Executive; North and West Belfast Trust; South and East Belfast Trust and Investing for Healthier Communities.

Belfast is one of forty-nine cities from twenty-six different countries to be designated to the WHO European Healthy Cities Network. The aim of the European Healthy Cities Network is to learn from and exchange experiences with other cities, and to promote good practice across Europe. Belfast joined the network as one of the first cities when the network was founded in 1988. Belfast is currently in phase three of funding from the network. The main task for phase three is to develop a City Health development plan, which was successfully completed in 2002.

Belfast Healthy Cities is a limited company by guarantee, with charitable status. The board of management consists of twelve members who are elected by the Belfast Healthy Cities Forum annually. The board carries financial and legal responsibility for the overall operation of the programme. The Forum consists of approximately 120 groups working in health-related areas in all parts of the city, and informs Belfast Healthy Cities on policy and strategy. Belfast Healthy Cities has a strong partnership approach.

This is exemplified in the following quote:

“Our method of work is to facilitate and support organisational change – we do not have operational responsibility that competes with that of our partners, but the healthy cities approach depends on the strengths of our partners” (Belfast Healthy Cities Fact Sheet, 2002)

### **NICHE – Cork**

The Northside Community Health Initiative (NICHE) is a partnership involving Knocknaheeny Family Centre and the Southern Health Board. NICHE currently receives funding from the Southern Health Board. It was funded under the Cork City URBAN programme up until June 2000. The focus of NICHE is on improving both community and individual health and well-being with a particular emphasis on the use of a community development approach. This involves recognising and building on the strengths that exist within communities as well as acknowledging the barriers (social, physical, psychological, cultural etc), which impede both individuals and communities from availing of health enhancing options (NICHE, 2001).

The work of NICHE is underpinned by a number of key strategies. These are as follows:

- Developing alliances based on a shared vision.
- Building on existing strengths within the community.
- Expanding the agenda of existing agencies and groups.
- Utilising relevant research and models of good practice in existing community development approaches.
- Promoting the Healthy Living Centre concept regionally and nationally.

- Linking with local, national and international networks which support the ethos of the project.
- Developing models of good practice for localising relevant national and regional policies.
- Disseminating information.
- Exploring in a local context, an equity and social inclusion agenda for health.
- Further refining the role of the Community Health Worker.
- Producing locally based, relevant research in co-operation with recognised research bodies.

(NICHE, 2001, p.4)

The ethos of NICHE is to recognise and value the contribution that can be made by all parties involved in the endeavour of promoting health and well-being within communities, local groups and local people, health service providers, locally based organisations and services as well as national and regional policies and strategies.

NICHE employs a community development approach to health. This is reflected in the role of the Community Health Workers (CHWs). The CHWs do not come from a medical background but rather instead from the communities in which the project is based. To date the CHWs have been successful in identifying and addressing barriers to participation in health promoting activities for groups and individuals. They have also played a key role in developing trust between the project and the target groups. NICHE is currently being evaluated in relation to its success in increasing knowledge awareness about health in the Knocknaheeny area.

### **Clondalkin Community Health Initiative – Dublin**

In March 2001, a health sub-group was formed by Clondalkin Partnership to identify health issues facing those living in North and West Clondalkin and to develop programmes in conjunction with the health authority to meet those needs. A needs assessment was carried out on the people of Quarryvale, which highlighted the negative impact of inadequate services, a poor living environment and poverty on people's health (Clondalkin Partnership, 2001).

The aim of the Clondalkin Community Health Initiative is as follows:

“To address health inequalities and inequity of access to health services in North Clondalkin, through the use of community development approaches and principles, thereby achieving equality and equity of health outcomes”

(Clonalkin Partnership, 2003)

The objectives of the programme are:

- To build on the consultative and participative processes to date
- To recognise the broader ‘social determinants of health’ model
- To compliment government health policy principles
- To tackle health inequalities and inequities

The following four main areas of health have been identified as needing action: disease reduction and prevention, improved child health, addressing broader/social health needs and addressing gaps in health infrastructure. The primary target groups are parents, women, young people, children and men. The programme is led by the following principles:

- Using community development approaches to involving communities in decision-making and in identifying health needs and priorities.
- Using partnership approaches.
- Using holistic approaches in order to tackle the broader determinants of health.
- Working towards the development of primary health care approaches in North Clondalkin.
- Tackling health inequalities and inequities in access to health.
- Using peer-led approaches to health promotion activities and health needs assessments.

(Clondalkin Partnership, 2003, p. 7)

The programme is funded under the RAPID<sup>2</sup> initiative. The programme is led by a local community partnership which consists of members from both statutory and community organisations. When the partnership group have established an action plan, they can then go on to form sub-groups whose will have the responsibility for implementing specific actions. The programme also aims to establish a local community health forum, which will ensure that community voices are represented throughout the whole process.

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<sup>2</sup> RAPID stands for Revitalising Areas by Planning, Investment and Development.

The programme is still at its early stages of planning. As a result, there are no results available on its rate of success. However, it has the potential to be a successful initiative given the level of planning and needs analysis, which has gone into it at an early stage. It also has a strong partnership base and places significant importance on community participation throughout the process.

## **Conclusion**

It would appear that the current political and policy environment in Ireland is conducive to implementing community development approaches to tackling health inequalities as there is much discussion surrounding community consultation, participation and the reduction of health inequalities. Whilst the concept of community development is not explicitly mentioned in the current health strategy this does not rule out government support and commitment to its application as a means to encouraging active community participation and consultation in improving the health of communities. Indeed, there is evidence of the value of community development in both the NAPS and the Health Promotion Strategy and more importantly a clear commitment on paper by the Government to engage in community consultation with regard to health care. Such government backing is imperative if community development is to be utilised to tackle health inequalities as Woods, Lake and Springett argue in relation to the HAZ initiatives in the UK “it has taken government recognition of the nature and extent of the health problems and inequalities that exist in the UK to begin to tackle the nations health ... the sea changes in government health policy supported by a belief in the importance of localities in decision-making processes have been instrumental” (2003; 65).

<b>Name</b>	<b>Clondalkin Partnership – Community Health Initiative, Dublin</b>
<b>Contact</b>	Fidelma Twomey <a href="mailto:Ftwomey@clondalkinpartnership.ie">Ftwomey@clondalkinpartnership.ie</a> 01 - 4576433
<b>When was the project established?</b>	March 2001
<b>How was the need identified?</b>	<ul style="list-style-type: none"> <li>- Public consultation for the Area Action Plan 2000 –2006.</li> <li>- Needs analysis in Quarryvale 2002.</li> <li>- Public consultation using Participatory Rapid Appraisal (PRA).</li> </ul>
<b>Aims and Objectives</b>	To identify health issues facing those living in North and South West Clondalkin and to develop appropriate responses using a social model of health.
<b>Target Groups</b>	Local people living in North Clondalkin, many of who experience multiple levels of poverty and social exclusion.
<b>Funding</b>	Funded by Clondalkin Partnership but submissions are made under the RAPID Programme and the initiative will be one of the lead agencies in implementing some of the health initiatives in the South Dublin County Development Plan (ten year strategy).
<b>Outcomes or achievements to date</b>	<ul style="list-style-type: none"> <li>- Research through public consultation.</li> <li>- Application under the RAPID Programme to set up a Primary Health Care Unit (staff pending).</li> <li>- Securing a room to run health promotion activities in Quarryvale.</li> <li>- Securing funding to employ a worker in 2003.</li> </ul>
<b>Level of community participation</b>	100 individuals 20 local groups.
<b>Implementation period</b>	March 2001 - 2006
<b>Evaluation</b>	Ongoing
<b>Has project tackled health inequalities?</b>	Yes. PRA was an equitable form of consultation for disadvantaged communities.
<b>Any other comments?</b>	New research on Primary Health Care to be carried out in December 2002 –March 2003. This will look at an operational model for North Clondalkin. It will take the current Primary Health Care Strategy into consideration.

<b>Name</b>	<b>Pavee Point - Primary Health Care for Travellers, Dublin</b>
<b>Contact</b>	Caroline Mullen <a href="mailto:phc@pavee.iol.ie">phc@pavee.iol.ie</a> 01 – 8780255
<b>When was the project established?</b>	1994
<b>How was the need identified?</b>	<ul style="list-style-type: none"> <li>- Consultation with Traveller women who identified needs while doing personal development course.</li> <li>- A peer led survey was carried out on 89 families.</li> <li>- The survey results and the needs identified were discussed with service providers.</li> </ul>
<b>Aims and Objectives</b>	<ol style="list-style-type: none"> <li>1. To establish a model of Traveller participation in the promotion of health.</li> <li>2. To develop the skills of Traveller women in providing community based health services.</li> <li>3. To liaise and assist in creating dialogue between Travellers and health service providers.</li> <li>4. Highlight gaps in service delivery to Travellers and work towards reducing inequalities that exist in established services.</li> </ol>
<b>Target Groups</b>	<ul style="list-style-type: none"> <li>- At the Local level - Traveller families in Community Care Area 6</li> <li>- At the National Level – Providing support to other PHC projects.</li> <li>- At the International level – Providing support to other gypsy, Traveller, Roma groups.</li> </ul>
<b>Funding</b>	Funded by the Traveller Health Unit in the Eastern Health Board.
<b>Outcomes or achievements to date</b>	<ul style="list-style-type: none"> <li>- Sixteen Traveller women trained as Community Health Workers.</li> <li>- The project has been replicated nationally.</li> <li>- Involvement in the National Traveller Health Advisory Committee.</li> </ul>
<b>Level of community participation</b>	Sixteen women and the Traveller community in Community Care Area 6.
<b>Implementation period</b>	Ongoing
<b>Evaluation</b>	The project has been evaluated and an Impact Assessment is planned for 2003.
<b>Has project tackled health inequalities?</b>	Yes, challenges the lack of access to health care services for the Travelling community.
<b>Any other comments?</b>	

<b>Name</b>	<b>Belfast Healthy Cities ‘Equity in Health – Tackling Inequalities’ Training Programme</b>
<b>Contact</b>	Ruth Fleming (Inequalities Programme Manager) <a href="mailto:ruth@belfasthealthycities.com">ruth@belfasthealthycities.com</a> 0289032881
<b>When was the project established?</b>	March 2002
<b>How was the need identified?</b>	Consultation process involving senior representatives from various statutory, voluntary and community organizations. Workshops were held in November 2001 and March 2002 to identify the needs of the various organizations.
<b>Aims and Objectives</b>	Aim: To assist statutory, voluntary and community organizations in promoting action to tackle inequalities in health. Objectives: <ol style="list-style-type: none"> <li>1. To encourage shared learning between organisations through a series of training days.</li> <li>2. To increase knowledge and awareness of partnership working, community participation, current indicators and impact assessment mechanisms.</li> <li>3. To assist organizations in examining existing practice in tackling health inequalities.</li> </ol>
<b>Target Groups</b>	Senior members of the statutory, voluntary and community sector as they can greatly influence future decision-making.
<b>Funding</b>	Funded by the Eastern Health and Social Services Board and the Belfast Regeneration Office.
<b>Outcomes or achievements to date</b>	<ul style="list-style-type: none"> <li>- Chief Executives have signed up to the Programme giving support to the participants they have nominated onto the Programme.</li> <li>- Two training days have been held – ‘Understanding Inequalities’ and ‘Monitoring and Evaluation’. A further five days are planned – one each month until March 2003.</li> </ul>
<b>Level of community participation</b>	47 Participants
<b>Implementation period</b>	October 2002 – February 2004
<b>Evaluation</b>	Evaluation is ongoing throughout the Programme. Participants will also complete a detailed questionnaire, which will assist them to evaluate their current work on tackling inequalities.
<b>Has project tackled health inequalities?</b>	This Programme works at a strategic level by providing participants with the knowledge to evaluate their organizational work in relation to tackling health inequalities and potentially make improvements if necessary.
<b>Any other comments?</b>	This Programme is unique for Belfast and is a great opportunity to get senior representatives together from many different organisations (statutory, voluntary and community) to share information, network and learn from each other.

<b>Name</b>	<b>Northside Community Health Initiative (NICHE), Cork</b>
<b>Contact</b>	Margaret Curtin <a href="mailto:nchi@iol.ie">nchi@iol.ie</a> 021 4300135
<b>When was the project established?</b>	1998
<b>How was the need identified?</b>	The 1991 Research Health Status Survey Report (1991) identified the area as experiencing a disproportionate level of health related problems. When URBAN funding became available the Local Family Centre, Community Development Project (CDP) and the Southern Health Board used the opportunity to apply for funding to address some of the health issues affecting the Northside area.
<b>Aims and Objectives</b>	<ol style="list-style-type: none"> <li>1. To explore effective mechanisms of consulting in relation to promoting individual and community health and well being.</li> <li>2. To develop innovative health promotion initiatives with local people through the use of community health workers.</li> </ol>
<b>Target Groups</b>	Residents of the Knocknaheeny/Hollyhill area – women, men, young teenage mothers.
<b>Funding</b>	Funded by the Southern Health Board.
<b>Outcomes or achievements to date</b>	The project has been very successful. NICHE list the following successes: <ul style="list-style-type: none"> <li>- Fourteen local people are training as massage therapists</li> <li>- A Men’s Health Group has been set up.</li> <li>- Increased support for young mothers.</li> <li>- Increased knowledge of health-related information</li> <li>- Greater uptake of physical activities in the area.</li> <li>- The role of the community health worker has been accepted by the Southern health Board.</li> </ul>
<b>Level of community participation</b>	Approximately 500 – 600 participants at various times during the year.
<b>Implementation period</b>	Current three year plan January 2001 – December 2003
<b>Evaluation</b>	Process evaluation underway (funded by the Dept. of Health and Children). Due for completion in April 2003.
<b>Has project tackled health inequalities?</b>	Yes, by making health promoting opportunities available to local people who would not otherwise have these options and by improving social interaction in a safe environment.
<b>Any other comments?</b>	Piloting the role of Community Health Worker has been an important aspect of the project.

## **Chapter 3**

### **Case Studies of Community Development Projects**

#### **Introduction**

This chapter proposes to provide a sample of community health development initiatives currently being delivered on an international level. Each of the case studies has been selected to highlight the different issues which community development can seek to tackle. The case studies look at health inequalities in general; specific groups who experience health inequalities e.g. the Travelling community, and topic issues affecting groups of people e.g. AIDS/HIV. The case studies examine community development activity in a number of countries including: Ireland, UK, India, New Zealand and Australia. Through this, it is possible to identify the different approaches and support for community development in the various countries selected. Each case study begins with a background to the project, which includes a discussion of the health policies, which influenced the establishment of the project followed by discussion of the implementation and evaluation of each of the projects.

#### **Case Study One: Diabetes Management**

The South Auckland Diabetes Project: New Zealand (Voyle, J. A., and Simmons, D., 1999)

Wolverhampton Asian Women and Diabetes Group: UK (Patel, G, 1999; Association of Community Workers, 1999)

#### **The South Auckland Diabetes Project**

##### **Background**

Similar to many other countries, New Zealand has a minority population, which have suffered alienation and oppression for many years. The 1996 New Zealand Census highlighted that the Maori account for 12.7% of the total population (Dept. of Statistics, 1997). The Maori population have poor health status when compared to the total population in New Zealand.

Traditionally, Maori have viewed health as an all embracing concept which emphasises the importance of spiritual, family, mental and physical aspects which provides a contrast to the predominant western model of health which focuses on the physical aspects of ill health.

Maori uptake of health services has been linked to the culturally insensitive manner in which services are delivered to this indigenous community. Maori leaders themselves argue that the poor health status of the Maori is part of their profile stemming from a breakdown in traditional tribal structures, societal alienation, poverty, and a loss of pride, spirituality and identity, which they trace back to the loss of their land and resources (Voyle and Simmons, 1999). Pomare and de Boer (1988) argue that rapid urbanisation has contributed to the poor health experienced by the Maori population while other researchers attribute their ill health to a loss of identity, unemployment coupled with a lack of education and skills within the community

The South Auckland Diabetes project endorses a community development approach, which is suited to a traditionally marginalised group such as the Maori community. Labonté (1990) suggests that:

“‘Enabling’ and ‘community’ are pivotal concepts for an integrated approach to health promotion as together they encapsulate a shift in power from bureaucracies to people. While there is no single path to achieving empowerment, community development stands out as one, which has much to commend it for advancing the health status of indigenous people”

(Voyle and Simmons, 1999, p.1050)

Bandura argues that the notion of self-efficacy<sup>3</sup> can be extended to collective efficacy, which implies that:

“The strength of groups, organisations, and even nations lies partly in people’s sense of collective efficacy that they can solve their problems and improve their lives through concerted effort”

(Bandura, 1982, p. 143)

## **Aims and Objectives**

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<sup>3</sup> The definition of self-efficacy is an individual’s belief in their ability to perform a particular task.

Durie (1994) states that there is a strong will on the part of the Maori to become more involved in the planning and delivery of health care for their communities. However, at the same time, there is a lack of knowledge and skills relating to the delivery of health care within the Maori community. Therefore, it is important to establish a partnership of qualified non-Maori people with Maori people in order to develop a health care system suitable to the needs of the community. The New Zealand government have begun to recognise the importance of incorporating Maori perspectives into the health services (Ministry of Health, 1997). This has resulted in the development of the South Auckland Diabetes Project (SADP). South Auckland is New Zealand's most industrialised and highly populated area. The primary health problem experienced by the Maori population is that of diabetes. A South Auckland study revealed an age-adjusted prevalence of diabetes among Maori of 4.8% compared with 2.0% for Europeans and 3.6% for Pacific Islands people (Voyle and Simmons, 1999). The South Auckland Diabetes Project seeks to control the diabetes epidemic. It is located at the local district hospital but operated independently. The project is based on the following assumptions:

- The historical context in which a person, programme or a policy operates has an important influence on the outcomes of the programme.
- The cultural context matters, a diversity of settings and programmes with a variety of styles, attitudes, and the goals is needed, commensurate with the diversity of people.
- The conditions of participation in the setting will have an effect on the empowerment of members.
- An organisation that holds an empowerment ideology will be better at finding and developing resources than one with a helper-helpee ideology.
- Locally developed solutions are more empowering than single solutions applied in a general way.
- The size of the setting matters. Settings that are small enough to provide meaningful roles for all members, yet large enough to obtain resources are more likely to create the conditions that lead to empowerment.
- Empowerment is not a scarce resource that gets used up, but rather, one that when adopted as an ideology, empowerment tends to expand resources. (Voyle and Simmons, 1999, p. 1040)

## **Implementation**

The project employs a community development approach, which is based on forming partnerships with the Maori communities and training them as community diabetes educators (Voyle and Simmons, 1999). The project focuses on diabetes awareness, nutrition, exercise, a diabetes support group and other health interventions. Simmons et. al., (1998) argue that the programme has “previously been shown to be associated with increased diabetes knowledge and activity rates, reduced dietary fat consumption and weight control among a non-Maori group (Voyle and Simmons, 1999). The project is based on a partnership approach. The partnership committee aimed to eventually hand over the control of the project to the Maori population, which they have managed to do quite successfully.

The partnership committee identified a number of recommendations, which they feel need to be considered when preparing to form a partnership between health professionals and the Maori community. Indeed, these recommendations or steps could be employed in the implementation of any community development and health project. These are as follows:

- Identify one or more key decision makers within the local community who can participate in the initial consultation process.
- Establish a clear and shared purpose. Negotiation is crucial, it is important to ensure that both groups have reached a common ground without hugely compromising their value system.
- Identify what each group can bring to the programme e.g. Health professionals have expertise in health knowledge while the Marae have expertise in local knowledge.
- Prepare a budget for the operation of the programme and examine the sustainability of the project when funding has been exhausted.
- Representatives from both parties should sign a formal written agreement. The group must not proceed to the next stage unless there is a shared support for the programme.
- The partnership committee membership should consist of Marae as the majority.

- In meetings, functions and all other activities relating to the programme, the committee should share a common goal of seeking to empower the community. Committee members need to be aware of their own power agendas that may be counterproductive to the aims and objectives of the programme.
- The partnership committee should formulate clear aims and objectives for the programme and ensure that all members have a clear understanding of the plan for the programme.
- Communication is of vital importance. Procedures need to be put in place, which ensure that all members, including funding agencies are aware of the progress, obstacles and issues presenting themselves to the operation of the programme.
- The programme should clearly support a community development approach throughout the planning and implementation of the programme with the eventual aim of the Marae owning and initiating the programme themselves.
- The process should seek to achieve a programme that is culturally appropriate, clinically safe and caters to heterogeneity among the target community.
- The process should seek to train Marae, so that they are equipped with the necessary skills and knowledge when it comes their time to run their own programme.
- Evaluation should be carried out in a manner which is suited to a community development approach e.g. process evaluation looks at the programme on an ongoing basis rather than medical research which can interfere with the work of the programme.
- A Marae liaison worker should be employed to work with the Maori population. The committee should administer payment in a way they consider fair. The committee should nominate the appointee although all participants should decide on the final appointment. The worker must be able to communicate well with the Maori community i.e. fluency in Maori language and knowledge of the cultural protocols. The worker should spend the majority of working hours in contact with the Maori community with a lesser amount of time spent with the professional health group. The worker should aim to work in conjunction with other members of the Marae community. This could serve as a valuable resource for the programme. The worker needs to report back to the committee on a regular basis to ensure accountability.
- Volunteers should be included in training opportunities as this has the potential to yield long-term benefits for the programme and its sustainability.

(Voyle and Simmons, 1999, p. 1047)

## **Evaluation**

The development of the project was to be accompanied by research to assess the effectiveness of the programme in controlling diabetes risk factors and to record information about the organisational processes surrounding the development of Marae-based health programme. The evaluation included quantitative evaluation of health outcomes and formative and process evaluation of the development of the project and the factors facilitating success. The first half of the evaluation involved monitoring baseline weights and measurements, self reports on eating and exercise habits and diabetes knowledge scores. The evaluator was a community psychologist who was also a member of staff of the project. Information was obtained through participant observation, with the researcher attending all meetings relating to the project. The evaluator also had a responsibility to promote the programme to other Maori community groups and leaders. Through this, the researcher came to meet many different members of the Maori community and so, learnt a great deal about Maori perceptions of their own health needs. The evaluator also conducted in-depth interviews with staff and individual members of the Maori population. Questions were formulated on the following themes:

- The role of the interviewee and their organisation within the Otara Maori community
- The nature of the interviewee's connection, if any with the present programme
- Perceptions of major health issues among Maori in Otara
- Lifestyles of Urban Maori, particularly aspects impinging on health status
- Interviewees knowledge of past health initiatives in Otara
- Differences between urban and rural Marae and particularly the challenges faced by urban Marae
- The strengths and weaknesses of the present pilot programme and how it could be improved
- The lessons that health planners might draw from past experience and from the experience of the pilot programme

(Voyle and Simmons, 1999, p. 1042)

The fact that the evaluator was an employee of the project had its advantages and disadvantages. The researcher had access to the target group but it was also felt by the programme team that there was a loss of autonomy and independence. A number of key issues emerged from the evaluation, which included the following:

- Conflicting paradigms of medical research, quantitative assessment and community development – The Medical model required that baseline research be undertaken prior to the Marae participating in any form of health education and/or community development. As a result, the partnership committee were delayed from implementing the programme.
- Building Trust – The lack of trust within the Marae community was identified as a huge issue. This was attributed to a history of colonisation, the restrictions placed on government funding, inadequate funding for the Marae to run programmes themselves, previous researchers failing to share information with research participants and a perception of self-serving agendas on the parts of bureaucrats and health service managers (Voyle and Simmons, 1999). In general, the Maori population had felt used in the past and were wary of any future involvement with their community. There was also conflict between the different Maori groups living in the area, each having their own interests and issues, which they wanted addressed.
- The value placed on a health programme – The research found that the more value the Marae place on health, then the more likely the programme would succeed. However, Maori tend to have many crises in their lives e.g. finding food and shelter and so, health fares low on their list of priorities. Maori women tend to put the health of their family before their own health needs. A lack of self-esteem was identified as a reason why Maori fail to value their own health. Maori have been conditioned to ‘waste not’ and so, find it difficult to adapt their eating habits to a healthier lifestyle. The older Maori lack the knowledge of basic health problems and needs.

As a result, the partnership committee had a difficult task on their hands to attempt to get the Maori to participate in the project and to take care of their health. Despite these difficulties, the programme has been successful in addressing the needs of the Maori community.

The project was successful in organising screening sessions, one-day health promotion events, diabetes prevention and healthy lifestyles and a diabetes support group. The main outcomes included the establishment of a health programme by the Marae Trust Board, a smoke-free Marae<sup>4</sup> was declared and the health promotion days attracted up to a hundred people. The project employed a Marae liaison worker to work with the Maori population. This was significant in that it provided the Marae with a spokesperson who in turn could enable them to become leaders in their own right.

The Marae have traditionally been a submerged community and this has resulted in feelings of powerlessness. The devolution of power was noted as a key aspect in the planning and implementation of the programme. Empowerment was the main aim of the programme combined with improving the health status and social and spiritual well being of indigenous people.

### **Conclusion**

Despite initial distrust between both partners at the beginning of the project, it has been a success to date. The Maori population have taken over the day-to-day running of the health groups and programmes. They have been empowered to improve their own health status. As Voyle and Simmons declare “Community development is an appropriate strategy because it incorporates empowerment both as means and end” (Voyle and Simmons, 1999, p. 1047). It is now aimed to highlight a community health development initiative in the United Kingdom. The Wolverhampton Asian Women and Diabetes Group provide another example of a community development approach to managing diabetes within a marginalised community.

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<sup>4</sup> Traditional meeting place

## **Wolverhampton Asian Women and Diabetes Group – UK**

### **Background**

Wolverhampton Asian Women and Diabetes Group (WAWDG) is a community health initiative organised by Asian women from the local community in Wolverhampton. The project involves Asian women in two discrete but complementary levels: a self-help group for women living with diabetes and a ‘helpers’ group of Asian women who act as interpreters and organisers. WAWDG seeks equal representation of women from the diverse Asian communities in Wolverhampton. The project has a holistic approach to health and self and community development is central to their activities.

Diabetes is four times more prevalent in the Asian community in the UK than it is in the white community. Despite this statistic health provision to this group of people is seriously under funded. The statutory health provision in the specialist Diabetes Centre in Wolverhampton had only one part-time Asian worker prior to 1999, who could communicate in the mother tongue of the majority of the Asian community. Patel (1999) states that within the Asian community itself there is sometimes a stigma attached to diabetes that leads to a culture of silence, which in turn makes it difficult for those living with diabetes to manage their condition in the best possible way. Patel argues the following:

“If people with diabetes have the information and knowledge of all aspects of diabetes control, they can make decisions about good diabetes management by adjusting either their medication or diet or exercise”

(Target, 1999, p. 10)

### **Aims and Objectives**

WAWDG came together as a result of a consultation undertaken by Wolverhampton City Challenge Health Project. As a result, a steering group was established and a self-help group was launched in March 1994. The values, which underpin the work of the project, are as follows:

- The project uses the experience of the women as a basis for learning for the group.
- WAWDG value this experience throughout their activities.

- The project encourages women to gain support and learn from each other and others.
- The project acknowledges and celebrates the diversity in the group.
- The project shares the tasks and decision making in a democratic and accountable way.
- The project acknowledges that the process is as important as the task.
- Finally, WAWDG seek to build upon women's impulse to learn and develop both for their own benefit and for that of the community at large.

(Association of Community Workers, 1999)

Women in the Asian community occupy a gendered position where expectations and material circumstances require that they balance domestic and caring responsibilities for others, often to the detriment of their own health needs. As a result, Asian women need support in diabetes care for themselves and for others.

WAWDG began at a time when diabetes care had developed to the extent that best practice in clinical care recognises the importance of patients' involvement in controlling their own condition. WAWDG is made up of Asian women who reflect the diverse Asian community in Wolverhampton. Patel states that it is important:

“To involve all the different elements of our communities to positively address the ambiguities of class, caste and an experience of inter-community tensions that may have its root in our experience of colonialism here and in our mother countries and in the diaspora”

(Association of Community Workers, 1999, p. 2)

## **Implementation**

Participation is the key to WAWDG's activities. It involves helping women to take control and join with other women in collective action to achieve change and acknowledge their shared experience of racism and discrimination in the UK and of gender inequality within their own communities (Association of Community Workers, 1999). The helpers at the group ensure that the non-English speakers understand and join in by running the activities in English, Punjabi and

Gujarati. The sessions are planned to incorporate discussions in 'pairs' and small groups to ensure that women feel comfortable in the discussions and feel able to contribute in a safe environment. WAWDG encourages its members to take on officer roles. To overcome reluctance to take up the roles, they use 'work-shadowing' which allows members to gain experience and to create a pool of women who can fulfill these roles in the future (Target, 1999). Outreach work carried out in community centers and religious venues is done in pairs to ensure the safety of the women volunteers and to improve their confidence.

WAWDG has examined the barriers to women's participation and has attempted to address some of the emerging issues. WAWDG arrange transport, pay travel costs and pay dependents' costs so that women attending the sessions can arrange carers. Self-help sessions are planned in great detail prior to the sessions and discussion, discovery and learning are at the session's core. Information is presented and disseminated in a clear and accessible manner. Guest speakers are invited to present information to the groups but must do so in a clear and easy to understand way and avoid medical jargon. Group members are involved in the session and are encouraged to question, comment and discuss the speakers comments. Through this information sharing, the women have gained strength and courage to attempt to challenge the power imbalances in society and to act together to achieve change.

### *The Helpers Group*

The helpers group consists of women who can speak English and one or more of the Asian community languages spoken in Wolverhampton. The initial group of women were recruited because they had previous experience of community development work. Many Asian communities are organised along very traditional, hierarchal and formal lines. This in turn has often has the effect of deskilling and demotivating Asian women (Association of Community Workers, 1999). As a result, WAWDG have developed a model of work, which recognises Asian women as the main drivers of change. The helpers group is made up of women who have the following skills and experience:

- They are bi- or tri-lingual
- They have trained others in the group on assertion skills

- They have taken part in community work skills courses
- They have experience in exercise and keep fit and have led sessions with the self help group
- They have learned and shared holistic and spiritual approaches to health

(Target, 1999, p. 11)

The helpers come from diverse backgrounds, which reflects both the diversity of the Asian community and of the group. Women in the helpers group have commented on the positive experience, which they have gained as a result of being a helper. Together the group applied for National Lottery funding. This involved defining the aims and objectives of the project and following through on their proposal. This has made a significant impact on the women's confidence to collectively seek and bring about change for their community.

### **Evaluation**

Evaluation has been carried out throughout the project. Each and every session is discussed and evaluated after it has been completed. Evaluation is carried out by the project workers in conjunction with the participants. As a result of their work with the Asian community, WAWDG recognised the high incidence of diabetes in the African Caribbean community.

In 1997, they initiated a new development entitled 'Black Women, Health and Community Work Skills'. They linked up with other organisations to develop the training course including:

- Mount Shiloh Health Advice Centre, an African Caribbean project dealing with hypertension and diabetes in the community
- Women Health Matters, a local women's health training and information service
- Federation of Community Work Training Groups, a national organisation interested in developing and disseminating good practice in black community work
- Wulfrun College, a local further education institute

(Association of Community Workers, 1999, p. 10)

A steering group was established which led to the development of a community work course for the African Caribbean community. The training consists of:

- Community work skills and practice
- Exploring issues of race and gender
- Assertion skills
- Learning about health issues

The strength of the course is that it has been developed and controlled by the community themselves. The course is accredited by the Open College Network in the West Midlands. The course has also led to the publication of a book made up of the presentations that the participants conducted on topics such as domestic violence, stress, body image and networking.

WAWDG have been successful in mobilising a community to take control not only of their health needs but also of their position in society. Participants in the project have commented on how much they value the opportunity to meet and share experiences of living well with diabetes and enjoyed both the information and social elements of the sessions (Association of Community Workers, 1999). Patel believes that the participant's capacity for learning, changing, self-organising and self-advocacy is just beginning. The helpers play an important role as role models to the Asian community. They have much to offer the group, in terms of their energy, commitment, ideas and experience.

The project has however, identified that despite a successful beginning, the sustainability of the project depends on funding. The projects activities often have to be skewed due to a lack of available funds. They also acknowledge the difficulties with meeting funders' demands, which often goes against the priorities of the project. The funding agencies often require the project to carry out activities, which may not be true to the project's original values and aims e.g. carry out activities, which do not bring about the empowerment of the participants. Despite these difficulties, the project aims to continue their good work and to continue to seek alternative funding which can enable the project to be sustainable. The project is currently funded by the National Lottery Charities Board for the period 2000 – 2003.

## **Conclusion**

The WAWDG seek to achieve better health and empowerment for the Asian community in Wolverhampton. The project workers note the implementation of the self-help group as one of

the projects greatest achievements. This is largely due to the helpers group who between them speak English and at least one other Asian language. The project also funds the costs for childcare/dependants care and arrange transport. These measures seek to address the barriers confronting Asian women when seeking to access health services. The Health and Community Work course has also enabled Asian women to develop their skills and knowledge relating to diabetes management and the establishment of self-help groups.

## **Case Study Two: Mental Health**

Maryborough Mental Health Promotion Project: Rural Mental Health in Australia (VicHealth, 2002)

### **Background**

In 1999, the Victorian Health Promotion Foundation (VicHealth) developed its Mental Health Promotion Plan 1999-2002, establishing a framework for the development of research and program activity over a three-year period. Vic Health defines mental health as the “embodiment of social, emotional and spiritual wellbeing. Mental health provides individuals with the vitality necessary for active living, to achieve goals and to interact with one another in ways that are respectful and just” (Vic Health, 2002, p. 12).

In the Mental Health Promotion Plan, Vic Health aims to achieve better health and well being across populations by:

- Focusing on improving the social physical and economic environments that determine the mental health of populations and individuals;
- Focusing on enhancing protective factors such as coping capacity, resilience and connectedness of individuals and communities in order to improve emotional and social wellbeing;
- Taking a whole-of-population approach, although different interventions may focus on specific population groups; and
- Measuring outcomes in terms of public policy, organisational practices, environmental shifts and health literacy.

(Vic Health, 2002)

A central part of Vic Health's work is a focus on three determinants of mental health: social connectedness, tolerance of diversity and economic participation.

- Social Connectedness includes: social and community connectedness, stable and supportive environments, a variety of social and physical activities, access to networks and supportive relationships and a valued social position. Brunner 1997 found that an individual's level of social integration and social support are powerful indicators not only of their mental health status but also of morbidity and mortality (Vic Health, 2002). As a result, the Mental Health Promotion Plan focuses on strategies to increase connections between individuals and communities.
- Tolerance of diversity includes: freedom from discrimination and violence, physical security and an opportunity for self-determination and control of one's life. For example, higher suicide rates among indigenous and same sex attracted young people have been attributed in part to discrimination on the grounds of race and sexual preference respectively (Vic Health, 2002). Therefore, the plan focuses on strategies that address racial discrimination, homophobia and ageism.
- Economic participation includes: access to work and meaningful engagement, access to education, access to adequate housing and access to money. McLelland and Scotton (1998) link poor mental health with limited access to important resources such as income, employment and education (McLelland and Scotton, 1998). The Plan aims to focus on strategies, which can enhance people's access to economic resources such as education, employment and income.

The Plan targets five population groups. These include:

- Rural communities
- Young people
- Older women and men
- Koori communities
- New arrivals to Australia

The Plan states that successful action to promote mental health can only be achieved and sustained with the involvement and the support of the whole community and the development of partnerships across a range of sectors.

Australia has one of the most urbanised populations in the world, with approximately 70% of the population living in capital cities or major metropolitan areas (AIHW, 2002). A report entitled 'Australia's Health 2002' found that overall, average death rates in rural and especially remote areas are higher than in metropolitan areas (AIHW, 2002). Australians living in remote communities lack ready access to many health services. They are also vulnerable to the effects of environmental disasters e.g. fire, droughts. Events such as these have been linked to higher rates of anxiety and depression as well as family breakdown. Rural communities are in decline. Privatisation of services, increases in the costs of fuel, industry restructuring and increasing globalisation has made it difficult for communities to sustain services and businesses. This decline has a significant impact on the mental health of rural communities.

As a result, VicHealth called for proposals under the Rural Partnerships in the Promotion of Mental Health and Wellbeing scheme. The scheme comprised eight projects each valued at \$90,000 with the Dept. of Human Services Rural Branch contributing an additional \$10,000 towards the cluster evaluation. The purpose of the projects was to develop innovative approaches or enhance existing strategies to more effectively respond to mental health and wellbeing in rural communities (VicHealth, 2002). It is now aimed to examine one of the projects in detail.

## **The Maryborough Mental Health Promotion Project**

### **Background**

Maryborough has been identified as an area suffering from disadvantage. However, East Maryborough has been particularly affected. There are higher rates of unemployment, lower school retention rates and a large number of people on low and fixed incomes than is the case in the greater Maryborough area. East Maryborough also suffers due to its geographic isolation and limited social connections from the Maryborough town center.

### **Aims and Objectives**

The project targets the residents of the Maryborough area. The Project was developed in order to mobilize what was recognized as a number of assets and skills, which could strengthen social connectedness within the Maryborough area. The objectives of the Project are as follows:

- To develop social infrastructure that will provide more opportunities for interaction and self-determination.
- To build the capacity and increased confidence of community members to participate in planning groups, community activities and other social forums.
- To reorient the focus of the community to support authentic participation of people from low socioeconomic backgrounds.
- To generate hope through planning and participation in community change.

### **Implementation**

The project involved building up the community capacity of the area. A local action group was established and training was provided to all participants. As a result, the action group implemented a range of initiatives and sought the support of local services and organizations to ensure their long-term sustainability. The Project placed huge emphasis on both the processes and the products of the initiative. One member of the group made the following comment:

“There was an effort in the Maryborough community to create a community through communication. A community newsletter was developed, for example, and it was distributed by hand.

This meant that the people in the group walked the streets and, in the process of delivering the newspaper, met people who were socially isolated. The content of the newsletter dealt with issues and concerns of the local people and the processes of distributing it contributed to the emerging sense of the community. The group expanded because of the newsletter”

(VicHealth, 2002, p.31)

The project is based on a partnership approach consisting of the following members: Maryborough Community House, Maryborough Rotary, Maryborough Adult Learning Centre, Goldfields Employment and Training, Goldfield Shire, Maryborough and District Accommodation Service and Maryborough Community Health.

### **Evaluation**

As mentioned previously, the Rural Partnerships in the Promotion of Mental Health and Wellbeing scheme was one of a series funded under the Mental Health Promotion Plan 1999-2002. Evaluation was noted as an important means of documenting and sharing the lessons learned, thereby contributing to knowledge in health promotion. VicHealth state that at the individual project level, evaluation provides a mechanism for funding bodies to monitor their investment and funded agencies with a tool for and reflecting on and refining their work (VicHealth, 2002). However, they argue that evaluations undertaken in the context of individual small-scale projects have a number of limitations. These are as follows:

- The resources available for evaluation seldom allow for more sophisticated and thoroughgoing evaluation, particularly of project impact.
- Individual small-scale projects offer limited power for assessing impact.
- Evaluations tend to be conducted and framed in response to specific local conditions and concerns. As a result, they have limited utility for assessing the contribution made by individual projects to the objectives of the broader programme of which they are a part. Similarly, the findings and lessons learned may not be readily generalized to other contexts.
- Findings recorded in evaluation reports of smaller-scale projects are difficult to disseminate.

(VicHealth, 2002, p.50)

As a result of these difficulties, VicHealth allocated funds to each of the schemes to carry out evaluation as a cluster. The aims of the cluster evaluation were as follows:

- To provide individual agencies with a common framework for reflecting, refining and reporting on their work which was coherent with the overall conceptual framework underpinning the plan.
- To enable VicHealth to draw on the experience of the projects to assess their impact on the intermediate outcomes it was anticipated would be achieved through implementation of the plan.
- To draw on the collective experience of the projects, hence increasing the power of the findings and the extent to which they could be generalized.
- To document the findings in a form in which they could contribute to broader understanding of the processes and strategies involved in mental health promotion and be disseminated to a wider audience.

The evaluation involved looking at the extent to which the projects were successful in: enhancing the capacity of organisations and practitioners to implement and sustain mental health promotion activity; building and consolidating partnerships to advocate for and foster mental health promotion activity; and enhancing individuals' access to the resources for positive mental health, specifically social connection, economic participation and freedom from discrimination (VicHealth, 2002, p. 52). The evaluation focused primarily on identifying models of good practice and the processes and strategies for achieving these outcomes. The evaluation drew on three sources of information:

- A common framework, developed collaboratively by the eight projects in cooperation with the external evaluator. Individual project reports were developed within this framework;
- A data tool developed for projects to report on project processes in the following areas:
  - Engaging individuals and the community;
  - Building ownership within the organisation and the community;
  - Forming partnerships;
  - Dealing with substantive issues of mental health promotion; and
  - Doing things and learning through action;

- A survey of partner organisations. This survey was designed to assess the extent to which projects had developed collaborative and sustainable partnerships.

(VicHealth, 2002)

The findings from the evaluation of the Maryborough project highlight a number of successes to date. These include the following:

- The project has engaged community members in developing a shared vision and identifying the strategies and resources to implement their vision. In total, 15 agencies, 40 workers and 140 residents contributed to the plan.
- The project was responsible for establishing a community action group who would be responsible for overseeing specific initiatives. The group currently has 20 active members. As a result of the action group, a number of members developed the skills and confidence, which enabled them to become active members on various other forums in the area.
- Training sessions were offered to community members in order to build their capacity, which in turn enabled them to participate in community building activities and thereby enhance their mental health and wellbeing. Issues such as group decision-making, press releases, meeting procedures, funding submissions and conflict resolution were covered in the training sessions.
- A range of social activities were held to reduce residents isolation and to encourage their involvement in the project e.g. a community garden was established for the purpose of enhancing social connection and physical activity.

During the course of the project, the mental health promotion framework became more familiar to community members. As a result, members began to identify other issues, which linked their sense of mental health and wellbeing with their physical environment. For example, the lack of access to transport was identified as an issue, which needed addressing. A community member made the following comment regarding public transport in the area:

“One of the things that caused social isolation in East Maryborough was the lack of a reliable transport system.

The project fought for and was successful in getting a community bus service re-routed. This directly addressed the lack of access people had to community services. The provision of the bus led to a review of transport provision and policies in the town”

(VicHealth, 2002, p.32)

The evaluation also noted the following developments.

- The Lance Reichstein Foundation is providing funding to the community action group, which enables them to employ a worker part-time.
- The project contributed to establishing the Strengthening Goldfields Project and has helped to ensure representation of East Maryborough in this Maryborough-wide community, strengthening project.
- Regional Solutions have contributed funding to support the development of the newsletter. A tutor was brought in to teach community members article writing, editing and production skills.
- Community fundraising has ensured investment in the community garden. The Council have also contributed e.g. by giving plants and soil.

Project workers from a community development background implemented the project. These skills were considered vital considering the emphasis on social connection. The project also contributed to tackling discrimination. For example, the development of the community garden ensured that everyone participated regardless of their background and so, enabled the project to model the importance of social inclusion and of working against discrimination (VicHealth, 2002). The project found that the use of the word ‘wellbeing’ was a more accepted concept rather than ‘mental health’, which was often seen as stigmatizing. Therefore, VicHealth argue that the choice of term may have contributed to the high level of community participation. Another key lesson learned from the project showed that capacity building led to the communities having more influence over the decisions affecting their lives and so, leads to sustainability. For example, a number of the Maryborough participants moved on to become members of local government structures (VicHealth, 2002).

In relation to the consultation process, it was found that auditing community assets has greater utility for establishing projects than undertaking community needs assessments. By enabling

participants to identify strengths, rather than weaknesses, these processes can contribute to enhanced self-esteem and confidence at the individual group and community levels. An auditing approach ensures that project activities are identified, displayed and implemented in ways, which are consistent with the overall intent of the funding Programme. It ensures accountability. In instances where projects are working with sub-population groups experiencing significant levels of discrimination and isolation from the broader community, mental health promotion activity is enhanced through focus on the strengths and abilities of the sub-population group involved (VicHealth, 2002).

## **Conclusion**

The major barrier to the success of the project was that it failed to bring about huge organisational change. Also, the projects cannot continue with only the promise of short-term funding. While most of the projects have been extended with project funding there is still a need for the agencies involved to make a more secure commitment. As VicHealth state “At some point, agencies needs to see mental health promotion activity as part of their core business rather than a short-term ‘add-on’” (VicHealth, 2002, p. 76). However, despite these difficulties, the Rural Partnerships in the Promotion of Mental Health and Wellbeing Scheme has been successful. The successes to date include the following: Communities pursuing the activities of the project on their own initiative, agencies changing their practices, the increased empowerment of the individuals and communities involved and the attraction of significant amounts of funding from different arms of government. As VicHealth state “The projects have been catalysts for change” (VicHealth, 2002, p. 76).

Case Study Three: Health Action ZonesHull and East Riding Health Action Zone: United Kingdom (HAZ, 2002; Sherriff & Webster, 2002; Bauld and Judge, 1999, 2002)

## **Background**

Health Action Zones (HAZs) are a central component of the UK government’s drive to improve public health and tackle social exclusion. The 1997 White Paper ‘The New National Health Service (NHS)’ described HAZ’s as a new initiative to bring together organisations within and

beyond the NHS to develop and implement a locally agreed strategy for improving the health of local people. In October 1997, the English Health Authorities were invited in conjunction with local authorities and other agencies to submit bids to become Health Action Zones (HAZs).

Twenty-six HAZs have been established by the English government in areas of deprivation and poor health to tackle health inequalities. HAZs are located across England, Northern Ireland and the Republic of Ireland and vary significantly in their local characteristics. In total in the UK, HAZs include 34 health authorities and 73 local authorities. However, they do range in complexity. Four main categories of HAZ configuration can be identified:

- Complex HAZs, which cover multiple local and health authorities. Examples include Merseyside and Tyne and Wear.
- HAZs, which involve a single health authority but multiple local authorities, such as Lambeth, Southwark and Lewisham and East London and City.
- HAZs, which comprise co-terminous health and local authority areas, such as Sandwell and Sheffield.
- Smaller HAZs, which cover unitary local authorities but only part of associated health authorities, such as Plymouth and Luton.

The communities do however face common problems of ill health and disadvantage. For example, HAZs account for 15 out of the 25 most deprived health authorities on the Jarman Under Privileged Area Index (Bauld and Judge, 1999).

### **Aims and Objectives**

The aim of the HAZ's is to tackle inequalities in health in the most deprived areas of the country through health and social care modernisation programmes. The three broad objectives of the HAZs are as follows:

- To identify and address the public health needs of the local area;
- To increase the effectiveness, efficiency and responsiveness of services;

- To develop partnerships for improving people's health and relevant services, adding value through creating synergy between the work of different agencies.

The HAZs aim to develop and implement a health strategy that tackles health inequalities and delivers within their areas measurable improvements in public health and health outcomes, and quality of care and treatment. They will also aim to increase sustainability by developing contacts with other zones, by disseminating ideas more widely, and by playing a major role in joining up existing initiatives.

### **Implementation**

HAZs represent a new approach to public health, linking health, regeneration, employment, education, housing and anti-poverty initiatives to respond to the needs of vulnerable groups and deprived communities.

HAZs are designed as partnerships between the NHS, local authorities, the voluntary and private sectors, and community groups. HAZs are coordinated locally by a partnership board. Performance is managed via National Health Service Executive Regional Offices. Through this initiative, the Department of Health has endorsed a bottom-up approach to working with communities. This approach is underpinned by seven guiding principles, which all HAZs have been asked to adopt and reflect in their plans and activities.

These include the following:

- Achieving equity – reducing health inequalities, promoting equality of access to services and improving equity in resource allocation;
- Engaging communities – involving the public in planning services and empowering service users and patients to take responsibility for their own health and decisions about care;
- Working in partnership – recognising that people receive services from a range of different agencies and that these services need to be co-ordinated to achieve the maximum benefit;

- Engaging frontline staff – involving staff in developing and implementing strategy, developing flexible and responsive organisations and encouraging and supporting innovation in service delivery;
- Taking an evidence-based approach – having a more structured, evidence-based approach for service planning and delivery as well as clinically effective procedures and interventions;
- Developing a person-centred approach to service delivery – developing services around the needs of people and delivering them as close to people as appropriate;
- Taking a whole systems approach – recognising that health, social and other services are interdependent and need to be planned and organised on a whole system basis to deliver seamless care and tackle the wider determinants of health.

[www.haznet.org.uk](http://www.haznet.org.uk)

## Evaluation

The national evaluation of the HAZs began in January 1999 and aims to be completed in 2003.

The approach to the evaluation is based on the following assumption:

“HAZs are intended to be learning organisations with a responsibility not only to achieve beneficial change but also to communicate results in a way which helps promote understanding about how and why outcomes emerge in the form that they do. Evaluation has a dual role to play in helping HAZs to communicate these results, both in terms of assessing processes and outcomes and assisting stakeholders to structure their own activities in a way which promotes investment in learning”

(Department of Health, 1999, p.15)

The purpose of the evaluation is to identify and review how HAZ agendas are formulated and implemented and to assess what they manage to achieve. A series of key research questions were compiled<sup>5</sup> as a framework for the evaluation. The evaluation is also informed by two theoretical assumptions. The first is ‘realistic evaluation’ which links the context of an initiative with the mechanism chosen to achieve change and the outcomes, which emerge over time (Pawson and Tilley, 1997). The second approach is the ‘theories of change’ approach, which aims to gain clarity around the overall vision of the initiative (Connell et. al., 1995). This theory

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<sup>5</sup> See Appendices

links the original problem in which the programme began with the activities planned to address the problem together with the medium and longer-term outcomes intended

Mackenzie et. al., (2002) state that HAZs resemble comprehensive community initiatives. The aims of comprehensive community initiatives are to: develop a variety of mechanisms to improve social, economic and physical circumstances, services and conditions in disadvantaged communities; and to place a strong emphasis on community building and neighbourhood empowerment. These characteristics pose a number of challenges when it comes to evaluating the HAZs. The reasons being as follows:

- HAZs have multiple and broad goals and therefore are not suited to evaluation methods that rely on a small number of outcomes.
- HAZs are very complex with multiple strands operating at any one time.
- The objectives and strategies of HAZs change over time in response to the community's needs and to changing policy requirements.
- Often HAZ interventions are rolled out before any formal evaluation mechanisms are put in place
- Improving health outcomes that are socially determined takes longer than the lifespan of an initiative and its evaluation.

(Mackenzie et. al., 2002)

As a result of the challenges presented when seeking to evaluate the HAZs, a theories of change approach was deemed a much more useful means of evaluation.

The general approach to the evaluation involves looking at a specific HAZ and reflecting on key aspects of the overall programme, workstream and individual projects. The next stage concerns specifying a rationale for intervening in relation to priority issues e.g. in response to a local needs assessment. The rationale should then clearly translate into clearly defined mechanisms, each with specified targets that should form part of a logical framework that leads in the direction of strategic goals (Mackenzie et. al., 2002)

Preliminary findings highlight positive results from the HAZs. They have been successful in developing synergy between agencies within the local health system. They have shown good

progress of involving local communities in the planning, implementation and delivery of HAZ programmes. It is now aimed to examine one of the twenty-six HAZs in order to present an example of the HAZ in practice.

## **Hull and East Riding HAZ**

### **Background**

Hull and East Riding HAZ has been in operation since the 1<sup>st</sup> of April 1999. It is one of the 15 second-wave Health Action Zones. The main focus of the HAZ is to target problems faced by older people, disabled people, children and young people, and those with mental health problems. A partnership has been established by East Riding of Yorkshire Council, Kingston upon Hull City Council, East Riding Health Authority, local trusts, the voluntary sector, the private sector and the Training Enterprise Council.

### **Aims and Objectives**

Hull and East Riding HAZ has an obligation to deliver the three strategic objectives set nationally for all HAZs (as outlined earlier). Hull and East Riding believe that meaningful change in health status can only be achieved by addressing issues both within health and social care, and across a range of social and environmental interventions. These changes can only be made by bringing about overall system change.

This requires a sustainable shift in the:

- Allocation of resources on the basis of need
- The design of services and interventions
- The assessment of need based on a more integrated and multi-sectoral approach.

Hull and East Riding state that the approach to this change is reflected in two key objectives set for the work of the HAZ. These are as follows:

- Health is incorporated as an important issue in the design and implementation of programmes across the broad front of social and environmental action, by clear demonstration of inter-agency links across a range of sectors.
- Improved access to health and social care services by increasing appropriateness, responsiveness, effectiveness and efficiency.

(HAZ, 1999)

The five ‘workstream’ areas for the HAZ include: service modernisation, partnership development, community development, organisational development and information development. In relation to service modernisation a number of key target groups were identified. These are as follows:

- Children and young people
- People with a disability
- People with mental health problems
- Older people

A set of aims and objectives relating to these groups of people were outlined in Hull and East Riding’s Implementation Plan (1999). It is aimed to highlight the key issues, which they plan to tackle through their work.

*Children and young people*

- Integrated sexual health – to improve sexual health across the HAZ area, with actions specifically targeted at areas of greatest need.
- Needs of children and young people – by targeted action within the overall strategic multi sectoral strategy for children and young people to deliver key improvements in health to children and young people suffering health inequalities.

*People with a disability*

- Progressive and radical whole system change which empowers disabled people to decisively shape their own life choices and develop their full potential

### *People with mental health problems*

- To improve mental health through service review and subsequent multi-sectoral change, focusing upon identified groups who suffer particular mental health inequalities.

### *Older people*

- To shift the balance of support and service for older people towards health improvement and retained independence in the community.

### *Smoking cessation services*

- To decrease the prevalence of smoking particularly amongst more deprived social groups.  
(HAZ, 1999)

In relation to partnership development, Hull and East Riding HAZ seeks to organise various partnership forums and events in order to engage the groups. They also seek to build new partnerships and to develop the capacity of all groups within the partnerships. The community development 'workstream' aims to build on good practice to ensure all areas can benefit from the community development approach to health. Through this, it is hoped that a community development approach will be adopted by organisations as a successful way of addressing the social determinants of health. The fourth strand of work involves looking at organisational development.

The HAZ aims change both the structures in which organisations relate and also the prevailing organisational culture. The final strand is concerned with information development. This relates to strengthening the information base and promoting community access to information about health and social care. It is now aimed to discuss the implementation of the HAZ in more detail.

## **Implementation**

Community development was identified as Hull and East Riding's key approach in which to focus their work. Community development is defined by the HAZ as:

“A range of practices dedicated to increasing the strength and effectiveness of community life, improving local conditions, especially for people in disadvantaged situations, and enabling

people to participate in public decision-making and to achieve long-term control over their circumstances”

(HAZ, 2002, p. 6)

The Hull and East Riding HAZ appointed five Community Health Development Workers located in, and managed by, the local Primary Care Trusts to work with individual communities to identify and address their needs. The first step of the process involved carrying out a mapping exercise to identify other workers, active community groups, facilities and related statistical information pertaining to the relevant geographical area. Work was then undertaken to facilitate the development of additional community activity, to identify needs and, wherever possible, support the community in achieving better health (HAZ, 2002).

A number of issues emerged from the research process, which reflect wider public health themes.

These include:

- Poverty – Poverty was identified as a barrier to accessing services. Unemployment and availability of jobs was noted as a concern as was debt management and the need to improve availability of jobs, training, and childcare to enable people to access employment.
- Transport – The cost, availability, uncleanliness and inaccessibility of public transport was raised and seen as a barrier to use.
- Crime – Community safety was identified as a priority and many people mentioned the importance of neighbourhood watch schemes and action on drug dealers.
- Housing – A key priority for people was action on problem tenants in both council and privately let properties.
- Physical Environment – There was a concern over declining neighbourhoods, which were seen to impact on the physical and social environment.

(East Riding and Hull Health Authority, 2000, p. 60)

Public Health funding was made available to the communities with the aim of addressing these identified areas of concern. The Community Health Development Workers are supporting the communities to develop projects, which tackle the issues affecting them and their lives.

The Community Development Foundation (CDF) was commissioned to provide support and professional development to the Community Health Development Workers. The CDF has also assisted in developing a local strategic approach to community development and in disseminating best practice.

The Community Health Development Workers have been involved in a number of initiatives in the HAZ area. Examples include:

- Consulting with parents and setting up parents groups.
- Organising and delivering courses around healthy eating, food preparation, eating on a budget and nutrition.
- Involved in the development of the local Patient Advice and Liaison Services (PALS), the aim of which is to open up another channel of communication between patients, carers and communities and the local NHS organisations.

(HAZ, 2002, p. 7)

The HAZ has organised Community Activist Training. This training will equip local people with the knowledge and skills to develop their communities. The HAZ has a 'Community Chest' (maximum of £500 per group), which helps to support community-based projects, which have a major contribution in improving the health and well being of local populations.

This funding can encourage the development of community-based groups and also, help increase the number of people participating the project e.g. the Bridlington Breast Cancer Support Group received a Community Chest Grant and produced a series of posters and cards publicising their group (HAZ, 2002).

The HAZ has been involved with developing bids to the New Opportunities Fund for a series of Healthy Living Centres. The aim of Healthy Living Centres is as follows:

“To promote good health in its broadest sense; helping people of all ages improve their well-being and get the most out of life. Users and local communities are encouraged to

play an active role in the design and the delivery of the projects to ensure that the focus of the schemes is on the needs of their communities”

(HAZ, 2002, p.9)

The bid has been successful with the establishment of an Older People’s Healthy Living Centre. The new centre includes an Intergenerational Project encouraging local schools to work with older people, a cyber café for ‘silver surfers’, an Ageing Well Project, which provides Senior Health Mentors to prevent or delay loss of independence.

Another example of the work supported by the HAZ is the Gypsy and Traveller Participation Group. Workers from different agencies were supported by the HAZ to set up a Gypsy and Traveller Participation Group in September 2000. The rationale for the group came from a recognition that this group traditionally live on the margins of society. The community experience marginalisation and discrimination. The Participation Group voiced their concerns to the Social Inclusion Team regarding the lack of consultation with the Gypsy and Traveller community. The Group carried out a number of community based events. These included:

- Photo-documentary project to get background information
- Education family day
- Computer bus
- Community apprentice
- Training in negotiation skills
- Whole system event to raise the issues and gain ownership by a range of statutory and voluntary agencies as well as the community itself

(Sherriff & Webster, 2002)

As a result of these activities, the Group revised their Terms of Reference for the Group. They met with the City Council to discuss the accommodation needs of the community and sought further funding for community development research. The group have identified the next steps as part of the process of supporting Traveller participation. These are as follows:

- Ensuring that consultation with this community becomes part of local democratic processes
- Increase participation in education
- Support the community apprentice
- Maintain the interest of the community for the sustainability of the project.

(Sherriff & Webster, 2002)

## **Evaluation**

The HAZs are being evaluated not only nationally but also locally. The local evaluation employs the same methods as the national evaluation while catering to the specific needs of the local HAZ. The University of Hull is currently carrying out evaluation of the HAZ community development strand in Hull and East Riding. The evaluation is being carried out in three different areas.

These are as follows:

- The provision of staffing resources for direct community development work and their gradual transfer and absorption into the Primary Care Trust structures. Essentially, this has involved the direct employment of five Community Health Development Workers. Early evaluation has confirmed the workers' commitment to community development as a bottom-up process, to working to the wider agenda and to addressing inequalities in health.
- The second area relates to indirect support for community development activity, which anticipates the building of infrastructural capacity. Evaluation has found aspects of this indirect support in the training and support given by the Community Development Foundation, in the Community Chest, and in the Community Activist Training Programme.
- The final area is concerned with ensuring that the community development philosophy is reflected within the work of other agencies, particularly those concerned with primary health interventions. This process of influencing the mainstream will be assisted by the

requirement to produce a Community Strategy and recent guidance on involving patients and communities in decision-making processes.

(HAZ, 2002, p. 11)

Hull and East Riding HAZ argues that there are a number of difficulties when evaluating community development activity. Firstly, community development workers believe that regeneration needs many years work and cannot come about in a specified time period e.g. one year. Secondly, the success of the project may not be a direct result of the work of the HAZ, it may have been influenced by other outside factors. Thirdly, it is difficult to define success. Indicators for success need to be drawn up in consultation with all members of the project and evaluation team. The fourth difficulty concerns evaluating the process of community development. Outcome based evaluation is not sufficient for community development based activities because while “an initiative may appear to reach the intended outcome, but the work may have been done in such a way that the community does not even own it, and therefore it does not achieve sustainability.

This is not a successful outcome in community development terms” (Holden and Craig, 2002, p. 28). These concerns have been taken into consideration during the undertaking of the evaluation on Hull and East Riding HAZ. The evaluation has not yet been completed but Holden and Craig (2002) state that there are encouraging signs of progress towards the achievement of the HAZ aims and intended outcomes. They acknowledge that the evaluation constitutes a very short timescale within which to identify the sustainability of certain changes. However, it will provide some preliminary pointers to future community development activity in the HAZ.

In general, HAZs have been considered successful initiatives. Sherriff and Webster state: “Most HAZs feel that the current national policy context for their work has had a major positive impact on their ability to deliver” (Sherriff & Webster, 2002, p. 4). Policy emphasis on community involvement, partnership working, joined up issues and tackling social exclusion and inequality have enabled benefits to be visible and clarified. Some of the benefits are as follows:

Benefits for communities include:

- An increase in opportunities to get and stay involved

- Comprehensive capacity building programmes to support and enhance ongoing involvement
- Facilitation of innovative approaches to involvement which has enabled participation by excluded groups
- Better information and awareness of health structures and organisations
- Services changed as a result of dialogue with agencies
- Sharing of resources through networking and new links
- Funding for initiatives which tackle the determinants of health
- Strengthening community organisations through additional support
- Support to deliver locally based services themselves

Benefits for individual health organisations such as Primary Care Trusts include:

- Increased knowledge of their local area and its population
- Gained new resources and new partners
- Raised profile of Primary Care Trusts
- Increase in organisational capacity to engage with their local communities – particularly where PCTs have been supported by HAZ staff to develop their community involvement roles and activities, with local partners
- Wider acceptance of a broader model of health has enabled organisations to address poverty and exclusion within a health agenda
- Health placed on partner's agendas in new ways
- Support for work to tackle health inequalities – community involvement work with excluded and disadvantaged communities has enabled those groups to inform the issues to be tackled locally in reducing health inequality.

(Sherriff & Webster, 2002)

## **Conclusion**

Statutory agencies have been made more aware of the importance of community involvement through HAZs. This has enabled them to try out new approaches to consulting and involving their communities and achieving greater feedback. HAZs are responding to needs identified by communities and this has led to improved access by excluded groups to decision-making processes. Many HAZs have noted that it is not yet known the benefits of community involvement in terms of health gain, better service provision and reduction in health inequalities. However, it is hoped that the pattern of increasing health inequalities will start to reverse. It is also aimed to increase partnerships with other health agencies. The HAZs initiatives plan to become mainstreamed. At present, the major issue presenting itself to HAZ is the uncertainty of funding in the future. This has consequences for long-term planning and effectiveness.

## **Case Study Four: Primary Health Care for Travellers**

Galway Travellers Support Group: Ireland (Dept. of Health and Children, 2002; Galway Travellers Support Group, 2000; Mahony, 2002; Pavee Point, 1996)

### **Background**

Travellers are an ethnic minority, a “community of people who have a long shared history” (McDonagh, 2000, p.26). They have a separate identity, culture and history to that of the settled community. Travellers are nomadic. They are native to Ireland; research indicates that Travellers have inhabited Ireland since the Twelfth Century. There are an estimated 30, 000 Travellers living in the Republic of Ireland (Pavee Point Fact sheet). Many factors contribute to the health problems experienced by Travellers. These include environmental hazards associated with living on the side of the road, lack of basic facilities, low levels of literacy (80% of Travellers experience literacy difficulties), inadequate health education, and discrimination by service providers.

### *Travellers Health Status Study 1987*

The only national data available on Travellers health is contained in the Travellers Health Status Study (1987). The study found that Travellers have an age profile similar to that of a developing country, 74% are under 25 years, while only 1.3% are over 65 years. Traveller infant mortality is three times higher than the national average. In a five-year period, for every settled child that died of a cot death – ten Traveller children died of a cot death. Life expectancy at birth for Traveller females is twelve years less than for settled females. Traveller men live on average ten years less than settled men. Mortality rates for Travellers are higher than those of the general population for all major causes of death. In a given year, male Travellers have over twice the risk of dying in a given year than their settled counterparts, while for females the risk increases more than threefold. Travellers experience higher levels of congenital abnormalities.

This fact serves to highlight the fact that culturally appropriate research needs to be undertaken in order to increase awareness about consanguinity<sup>6</sup>. Travellers are now only reaching the life expectancy that settled people had in the 1940's.

### *Travellers uptake of Health Services*

The Centre for Health Promotion in NUIG (1995) looked at Service Provision to the Travelling Community. O' Donovan et. al., carried out a survey on a number of Travellers and found that Travellers experienced difficulties accessing services for the following reasons:

- 36% of Travellers had difficulties getting a doctor out on call
- Difficulties (80% experience literacy difficulties) filling out medical cards and forms
- Discrimination by staff – being put down by doctors and nurses
- Difficult to queue in a surgery when you have lots of children
- Confusion about immunisation - irregular attendance at school meant that many Traveller children were not receiving the full complement (only 28% had received the full complement)
- Lack of information about how to use the health services

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<sup>6</sup> Defined as marriage between second cousins or closer.

- Reluctance of doctors to accept Travellers on their list
- Lack of transport

The Survey also found the following in relation to Traveller women's health:

- There was a 35% complication rate during pregnancy (National rate 20%)
- Less than a third of mothers went back for a postnatal check after their last baby
- Much of the provision for formal health education is provided on an ad hoc basis
- 20.5% had attended a health education programme and found it helpful for their own and children's health

(O' Donovan et. al., 1995)

#### *National Traveller Health Strategy 2002-2005*

In 1995 the Task force on the Travelling Community recommended the drawing up of a national strategy to improve the health status of the Travelling Community. The Strategy which has taken eight years to complete aims to improve the health status of the estimated 25,000 Travellers in the State. The Strategy recognises that Travellers have a right to appropriate access to health services, which take into consideration Travellers' particular needs, culture and way of life. The Strategy proposes 122 actions to be implemented by the end of 2005. The Government have pledged € 8.2 million to ensure that this ambitious target is reached. The Strategy acknowledges that the contribution of Travellers to health service planning, promotion and delivery is vital in order to achieve equity in the health care system for the Travelling community. The need for a community development approach within the health services is recommended as essential. It states as follows:

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

(Dept. of Health and Children, 2002, p.10)

Partnership between Travellers, Traveller organisations and health care personnel is to be established and the role of the Traveller Health Unit is to be strengthened. Awareness training is

to be provided to health care staff in relation to Traveller culture. This is a positive step towards making health care services culturally appropriate. The Strategy also acknowledges the importance of Traveller proofing all policies relating to Travellers health. This system of Traveller proofing all national and Regional health initiatives, which impact on the health of the Travelling Community, is to be introduced before September 2002. This has not yet been implemented (Dept. of Health and Children, 2002).

A Traveller Needs Assessment and Health Status Study will be carried out to develop and extend the indicators collected in Barry's 1987 Traveller Health Status study. This will provide up-to-date data on the health status of the Travelling Community.

### **Pavee Point**

Pavee Point<sup>7</sup> is the leading Traveller organisation in Ireland. Pavee Point is a non-governmental organisation committed to the attainment of human rights for Travellers. It is comprised of Travellers and members of the settled community, working together to address the needs of the Travelling community in Irish society.

The Primary Health Care (PHC) Programme for Travellers was piloted in Pavee Point in conjunction with the Eastern Health Board. In the early 1990's, a group of Traveller women who were involved in a personal development course in Pavee Point identified the need for health care skills for Travellers. The women wished to improve the health status of Travellers through information and training, which would focus particularly on the causes and prevention of illness amongst the Traveller Community. PHC was identified as an approach that could be piloted to facilitate Traveller participation in health due to its emphasis on empowerment, community participation and partnership.

Pavee Point submitted a proposal, in consultation with the Traveller women to the Eastern Health Board for the setting-up of a PHC project for Travellers. The proposal was accepted and in 1994, the PHC project was established as a pilot initiative. The project set out to use

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<sup>7</sup> Pavee is a word used by Travellers to describe themselves.

community development strategies in order to achieve the involvement of the Traveller Community in identifying their health needs and the barriers they experience when accessing health services. Traveller participation is encouraged at every stage of the project, from initial planning right through to evaluation of the project. The project has four main objectives:

- To establish a model of Traveller participation in the promotion of health.
- To develop the skills of Traveller women in providing community-based health services.
- To liaise and assist in creating dialogue between Travellers and health service providers.
- To highlight gaps in health service delivery to Travellers and to work towards reducing inequalities that exist in established services.

(Pavee Point, 1996, p.10)

To date, the PHC project has had many successes. Sixteen Traveller women have received accredited training as Community Health Workers (CHWs) and are currently employed by the Eastern Health Board but are based in Pavee Point. The CHWs have generated greater awareness of the health needs of the Traveller Community. They have developed culturally appropriate health education materials e.g. posters on breastfeeding, immunisation, oral health. These posters can be understood by looking only at the pictures. Therefore, they do not exclude members of the Travelling Community who may be illiterate. The CHWs have also produced videos, which provide information on Travellers health. The CHWs organised well-woman clinics, which are specifically targeted at Traveller women. The CHWs provide in-service training to health professionals on ways of making the health services more culturally appropriate. They also provide health education to Travellers at the different halting-sites. The CHWs have themselves learned to take control of their health. They have been empowered through their involvement in the PHC project. They are active in lobbying for change and they represent Pavee Point on a number of different committees e.g. the National Health Network.

The PHC project has been replicated in a number of other areas around Ireland. Pavee Point state that it is important that the replication of the project is not equated with duplication (Pavee Point, 2000) but that each project take the principles of the project and apply them to their own area/project. It is now aimed to discuss the PHC programme as adopted by the Galway Travellers Support Group.

## **Galway Travellers Support Group**

### **Background**

The Galway Travellers Support Group (GTSG) is a partnership organisation of Travellers and settled people working together to achieve equality and self-determination for the Travelling community in Galway City. The GTSG's vision statement is as follows:

“The GTSG aims to achieve full equality for Travellers and the participation of Travellers in social, economic, political and cultural life as well as the broader enhancement of social justice and human rights”

(GTSG Annual Report, 1999, p. 4)

The work of the GTSG is based on the principles of community development. The project is funded under the Dept. of Social, Community and family Affairs Community Development Programme (CDP). It also receives funding from the Western Health Board, FAS, Galway City Partnership and other organisations.

### **Aims and Objectives**

The PHC programme for Travellers in the GTSG strives to empower Travellers to take ownership of their health. The Task Force on the Travelling community (1995) states:

“Traveller organisations have an important contribution to make in the targeting and in the appropriate delivery of health services to the Traveller community”

(Task Force Report, 1995, p. 149)

The aims of the PHC programme in the GTSG are as follows:

- To pilot a culturally appropriate PHC initiative in Galway, which could be used as a model for health promotion elsewhere in the region.
- To identify and explore appropriate responses to the health status of the Traveller Community.
- To provide opportunities for Traveller women to develop skills in PHC practice and become involved in the planning, implementation and evaluation of health programmes.

- To address the inequalities, which exist in terms of health care provision for Travellers and promote creative ways of developing dialogue between Travellers and health service providers.

Following on from the aims of the programme, the objectives include the following:

- To provide a training course for 16 Traveller women in the provision of community based health services.
- To identify the needs of Travellers with regard to their specific health needs and health service provision in Galway.
- To empower Travellers to take up positions of leadership within their own community through developing their knowledge, skills and confidence.
- To disseminate information to Travellers and Traveller groups on issues relating to health care.
- To promote the concept of Primary Health Care amongst the Traveller Community in Co. Galway in order to ensure their support for the programme.
- To increase the participation of Travellers in the activities of the Traveller organisation and community development work in general.
- To develop structures, which will facilitate ongoing contact with and co-operation between health service providers, Traveller organisations and other Traveller groups in the region and the Traveller community as a whole.
- To develop culturally appropriate training modules and material for Travellers, which will enable them to participate fully in the proposed training programme.
- To inform Travellers involved of key policy areas related to health and to work with them in seeking to impact on policy change and engage in dialogue with policy makers.

(Galway Travellers Support Group, 2000, p.6)

The expected outcomes of the PHC programme in the GTSG are that:

- There will be trained, skilled CHWs promoting a model of Traveller participation in the promotion of health

- Job opportunities will be made available for CHWs within the health services.
- The CHWs will work in conjunction with health care personnel.
- There will be greatly increased accessibility and acceptability of health services to the Travelling Community resulting in increased uptake of preventative and aftercare services in particular.
- The CHWs will work in partnership with health service providers developing an integrated approach to improving the uptake of services.

(Galway Travellers Support Group, 2000, p.6)

### **Implementation**

A community development approach underpins the work of the PHC programme to ensure meaningful Traveller participation and that Travellers are involved at all levels of decision making. The programme is an innovative and creative way of responding to health issues affecting Travellers.

There are sixteen participants on the scheme in Galway City, training to become health care workers. The participants represent members of the different Traveller families in Galway City with the intention that they represent a cross section of their community coming from a range of different types of accommodation: group housing, permanent halting sites, temporary sites, transient sites and standard housing. Various Government Reports have highlighted the need for Traveller-led initiatives. Experience has shown that where members of a community are actively involved themselves, the outcomes are much better. The National Traveller Health Strategy (2002) states:

“The inherent approach is to work ‘with’ the Traveller community in order to develop a PHC project based on the Traveller community’s own values and perceptions so that positive outcomes can have a long-term effect”

(Dept. of Health and Children, 2002, p.59)

The Traveller Health Unit was set up in the Western Health Board in 1996 with the aim of improving the quality of life and health of Travellers. As a result of consultation with the

Traveller Health Unit and the Travelling Community, the Primary Health Care (PHC) training for Travellers began in Galway on the 24<sup>th</sup> of January 2000. The PHC programme was open to all Travellers over twenty-three years of age. This criterion was selected based on the entry requirement guidelines for mature students accessing third level education (GTSG, 2000). Representation from all family groups within Galway city was a feature of selection to ensure that all Traveller families would have a health care worker to represent them and their locality.

The PHC programme will run for a total of five years at the end of which all 16 trainees will receive certification as health care workers and be employed by the Western Health Board to work as health care workers within their own family groupings. The participants are currently in their third year of the programme. The programme is based in the GTSG and is carried out during the hours 9am to 1pm, Monday to Friday. A community development approach is integral to the programme. It ensures meaningful participation by the Travelling Community.

The programme adopts a partnership approach working closely with other agencies, which, includes FÁS, Galway VEC, Galway Adult Literacy, and the wider Travelling Community to ensure a holistic approach is undertaken in order to improve Traveller health. The programme is co-ordinated by a Public Health Nurse and a Community Development Worker. The PHC programme is managed by a steering committee consisting of members of the Galway Traveller Support Group management committee, the Traveller Health Unit, Western Health Board, the project co-ordinators and participants on the Training Programme.

The foundation phase in year one focused on an introduction to Personal Group development, Community Development, Primary Health Care, Traveller Issues and Literacy and Numeracy training. The following years focus on building on the knowledge gained in year one<sup>8</sup> e.g. learning about health promotion and issues such as racism and discrimination. The final year of the programme enables the participants to work out in the community as CHWs with full support from the co-ordinators on the programme. The learning process occurs in a number of different ways e.g. experiential learning, group discussions, workshops, project work, work placements.

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<sup>8</sup> See Appendix two for outline of modules.

## **Evaluation**

The PHC programme is subject to external evaluation pre-training, mid-training and on completion of the course. The Western Health Board is responsible for the overall evaluation of the programme. The evaluation looks at the effectiveness of the training programme and whether the programme has reached its objectives of training members of the Traveller community as Community Health Workers. The evaluation is concerned with looking at three main areas:

- The need and relevance of the training.
- Any obstacles to the setting up of the training.
- Changes in the level of knowledge about health issues, community development and general healthcare as a result of the training.

The methodology employed for the evaluation includes discussions with course participants and a survey of participants and evaluation of each phase of the programme. The role of the discussions is to facilitate the planning of future modules and provide additional insight into the results of the subsequent elements of the research. The Department of Health in conjunction with the Traveller Health Unit have developed a questionnaire, which is administered at specific points throughout the programme. The questionnaire asks for information on participants' perceptions of each element of the training, whether the training has equipped them with the necessary knowledge and skills and whether they believed there were any particular aspects of the training that could be changed/improved. All the information is treated in confidence. The external researcher records the findings of the evaluation at the end of the programme and they are made available to those interested. The co-ordinators of the programme also carry out ongoing monitoring and evaluation to ensure that they are meeting the objectives of the programme. Weekly report sheets are completed by the co-ordinators and submitted to FÁS who in turn carry out their own assessment and evaluation. The co-ordinators of the programme are evaluated regularly through supervision and feedback from the trainees. This ensures that the work is carried out to a high standard at all times.

Mahony (2002) carried out research on the work of the PHC programme in the GTSG. The researcher was based in the GTSG for a period of four months and so, had an opportunity to observe everyday events undisturbed as they occurred. A total of four interviews were conducted. These were carried out with people who have experience of working with Travellers, either on the ground or through research. A focus group was carried out with the members of the PHC programme. This use of lay knowledge is vital to the research because it is:

“Rooted in the places people spend their lives, it has theoretical significance for our understanding of the causes of health inequalities...presents a ‘privileged’ form of expertise about inequalities in health”

(Popay et al., 1998, p. 621)

Secondary sources used for the purpose of this research are mainly in the form of various books, journals, Government reports and publications by Traveller organisations. It is aimed to present the main findings in relation to the importance of a community development approach to Travellers health.

The research found that community development has a huge role to play in reducing Travellers health inequalities. In order for real change to come about for Travellers, it is vital that Travellers are involved in the process of bringing about that change.

“Unless people themselves are actually involved, we’re not going to get very far because the solutions will be seen to be coming from outside and not from within the community itself and after all, the people who know their own community are the families themselves”

(Mahony, 2002, p.85)

It is important to adopt community development approaches to Travellers health because it involves enabling Travellers to “become involved in shaping their own destiny in many ways, not just in terms of their health” (Mahony, 2002). The PHC project is a prime example of the value of community development in reducing Traveller women’s health inequalities.

“It’s led by the people themselves, it involves collaboration across different agencies, it is empowering in essence, it involves the delivery of information but in a way that is not intended to be coercion”

(Mahony, 2002, p.86)

The participants were asked about their views on the PHC programme and to identify the strengths and weaknesses associated with the programme. The strengths of the PHC programme reflect the role of community development strategies in reducing health inequalities because the PHC programme is a community-led initiative. One of the strengths of the programme is that it is a Traveller initiative.

“Its run by the women basically, a lot of the planning and the work that went into the project is responding to their needs, their perception of what is needed, so I think the strength is that we [Pavee Point] would listen and try to respond to what is needed, so I think the strength is that we would listen and try to respond to what is needed and that’s a huge strength”

(Mahony, 2002,p.87)

The PHC project in Pavee Point has been established since 1994. The CHWs are based in Pavee Point for the past eight years. They have great respect in their communities and are always available for support and advice.

“You could say that they work within programme hours but they don’t, people are always in for informal information and they are like an advice centre for people who need to know anything about health, they would probably come to the women first, that’s an advantage because they are on the ground twenty-four hours, even though they are not supposed to be but they are prepared to do what a health service can only do in 9 to 5 hours, people feel that they can go into talk to them”

(Mahony, 2002,p.87)

The CHWs are Travellers and so are in the best position to help Travellers because they understand their culture. The research found that “a Traveller will talk to a Traveller, the

way a Traveller understands, so it's very clear and there's no ambiguity by what is being said" (Mahony, 2002, p.88).

The project is a partnership project. This is vital to the success of the project.

"I don't think we could do it on our own, we were talking about accessing services, closing gaps, understanding each other, and that needs to have two sides to it"

(Mahony, 2002, p.88)

The PHC programme is a good initiative "because it starts with the Traveller people and has evolved in consultation with the Traveller Community in the Dublin area, which is one of its great strengths" (Mahony, 2002, p.88). The main strength of the PHC programme is that it emerged out of a need identified by the Travelling Community. It was not imposed on the Travelling Community. They initiated the concept of developing health care training for Travellers. They were motivated to improve the health status of their community.

The CHWs have direct access to their community. They can help Travellers to overcome many of the barriers associated with accessing health services. For example, they speak in a language that is clear to Travellers, they are best equipped to ensure that services are culturally appropriate, they can help Travellers fill in forms and they can provide health information. The PHC programme helps Travellers to develop that voice to its full potential. The PHC project in Pavee Point has been running for the past eight years. This is a strength in that the project has trained and employed Travellers as CHWs. The PHC project in Pavee Point has had a number of achievements to date such as the uptake of dental services and an increase in women attending the Well Woman Clinic for check-ups. The PHC programme offers a way of working in partnership with health service providers and personnel.

## **Conclusion**

Effective participation can lead to real change for those who are socially excluded. PHC acknowledges that the community participation is important because it ensures that 'real' health needs are identified and addressed by those most affected. As the Community Workers Co-Operative states:

“If the voice of those who need resources and require elevation in society is not being heard in the formulation, implementation and monitoring of social change then it is not surprising that decisions taken about them and their needs are often wide of the mark”

(CWC, 2001, p.10)

The GTSG believe that the PHC programme is vital because:

“There is a need for health and social gain which can best be achieved through a multi-sectoral integrated approach, which is client centred, quality driven and operates to promote client autonomy and empowerment through participative structures”

(Galway Travellers Support Group, 2000, p.6)

However, there needs to be coordination at the national and the local level. The National health services need to see citizen participation as an asset and to be responsive to the needs identified by the community. The National services need to develop policies, which support local initiatives and to strengthen independent community development work in health (Crowley, 1999). Discriminatory practices need to be tackled in order to increase participation in the health care system. At a local level, there is a need to actively involve minority groups and to develop an accountable, networked community action on health (Crowley, 1999). Crowley argues that if the above is implemented, it should result in a more democratic and accountable health service.

## **Case Study Five: Community Responses to HIV/AIDS**

### **The Sonagachi Project: Calcutta, India (Madhu, 2000; Jana et. al., 1999)**

#### **Background**

The AIDS epidemic claimed more than 3 million lives in 2002, and an estimated 5 million people acquired HIV in 2002 – bringing to 42 million the number of people globally living with the virus (UNAIDS/WHO, 2002). WHO states that the evidence of the impact of AIDS/HIV is undeniable. The virus has resulted in countries losing resources and capacities on which human security and development depend. It is important to prevent the spread of the virus, so as to ensure that countries do not suffer any more than they already have (UNAIDS/WHO, 2002).

Rhodes (1996) states there are two underlying reasons for developing community action interventions as a method for HIV prevention. The first concerns the inherent limitations of individually focused, one-to-one interventions in adequately reaching target populations within a specified community or social network. Community development in health aims to encourage a system of peer support and participation, which eliminates the above difficulty. Secondly, interventions targeting individual behaviour changes alone are limited because they do not necessarily encourage the social conditions in which individuals can actually exercise ‘choice’. Community based responses to HIV/AIDS bring about changes in the community norms and practices which impede individual attempts at risk reduction. Community development encourages not only individual change but also ‘community change’ – change which is oriented towards groups, networks or communities of individuals (Rhodes and Hartnoll, 1996). It is aimed to examine community responses to HIV/AIDS in India in order to highlight community activity in the developing world and also to highlight community development responses to HIV/AIDS.

## *India*

India is the largest parliamentary democracy in the world. It has an independent judiciary, a free press and political armed forces. The population for India in 2001 stood at 1,027,015,247 people. The population of the country rose by 21.34% between 1991 and 2001 (Census of India, 2001). Poverty is widespread. A total of 320 million people live in poverty – a figure higher than the total population in 1947 and over half the population live on less than a \$1 a day. Those experiencing poverty suffer disproportionate ill health, the poorest 20% are almost five times more likely to suffer from TB and overall three times more likely to suffer from malaria. The levels of poverty are closely associated with caste, age at first delivery, female education, access to electricity and location (DFID, 1999)

Health indicators for India are poor. Average life expectancy is 62 years and is higher for men than women. Infant and child mortality rates are high at 77 and 102 per 1,000 live births respectively. In the 0 to 4 age group the average burden of disease is almost four times that in China and 16 times that in established market economies (DFID, 1999). The major sources of ill health are infectious and parasitic diseases, respiratory illness and perinatal causes.

The medical system is based on publicly provided services free at the point of delivery.

Infrastructure and medical staffing levels are based on population-based norms with the intention of providing equitable access. Current policy weaknesses include an over centralized supply led system with almost no delegation of financial and administrative powers to districts, duplication, a lack of capacity for devising levels of financing and a complex system of financing, a rapidly growing and largely unregulated private sector and low quality of public services in the public sector (DFID, 1999). The government are currently considering reforms involving decentralization and devolution with a special focus on local government and community needs planning.

### *HIV/AIDS in India*

HIV was introduced into India at a later date than much of the rest of the world. However, the epidemic is extensive, with rapid growth in some geographic areas. Studies of high-risk populations (commercial sex workers, intravenous drug users, and sexually transmitted disease patients) show high and rapidly rising rates of HIV infection exceeding 50% in some parts of the country (Adlakha, 1997, p. 2). An estimated 3.97 million people were living with HIV at the end of 2001 – the second highest figure in the World after South Africa. New behavioural studies in India suggest that prevention efforts directed at specific populations (such as female sex workers and injecting drug users) are paying dividends in some states, in the form of higher HIV/AIDS knowledge levels and condom use (UNAIDS/WHO, 2002, p.7). It is aimed to discuss a community development intervention for reducing HIV in Calcutta, India.

### **The Sonagachi Project – Calcutta**

#### **Background**

The Sonagachi Project (also known as the STD HIV Intervention Programme (SHIP)) is recognised by UNAIDS as a ‘best practice’ model for its use of a community development approach to empower sex workers to take individual and collective action to reduce their vulnerability (DMSC, 2000). In 1992, the World Health Organisation funded the National AIDS Control Organisation to undertake a three-month community based cross-sectional survey in Sonagachi, one of the oldest and largest red light districts in Calcutta, to assess the prevalence of STD’s and HIV among sex workers (WHO, 1992). The research looked into issues of social demography of the locality, mapping the practice of sexual behaviour among sex workers, their clients and partners, and estimating the prevalence of STDs and HIV among them. Following the survey, an intervention programme was started in the area with the objective of controlling the spread of STDs and HIV among sex workers and their clients and partners.

## **Aims and Objectives**

The intervention programme started with three principal components.

- Provision of health services including STD treatment from a central clinic in the area.
- Dissemination of information, education and communication (IEC) regarding prevention of STD/HIV transmission and;
- Promotion of condom use.

(Jana et. al., 1999, p. 3)

The Project was put into operation through a collaborative network of government and non-government institutions. A group of sex workers from the locality were employed as peer educators. Their role being to disseminate information leading to behaviour change, distributing and promoting the use of condoms among sex workers, and referral to and provision of treatment of STD and general health problems. However, their focus soon broadened to address structural issues of gender, class and sexuality. Unique to the programme is that it gave sex workers a central status within the programme right from the beginning. The sex workers themselves decide the programmes strategies. Twenty-five percent of managerial positions are reserved for sex workers and they hold many key positions within the project. The project uses a flexible approach so that the programme can be adapted to the changing circumstances and needs articulated by the community. In this way, the project could be remodeled if deemed necessary. The Sonagachi Project followed a number of guiding principles, which shaped their approach to the work undertaken. These are as follows:

- From the very beginning there was no attempt to ‘rescue’ or ‘rehabilitate’ sex workers. They were accepted for what they were. Their capabilities as human beings and workers were recognized and respected. The basic approach to the project can be summed up as the three ‘R’s: Respect, Reliance and Recognition. That is respect towards sex workers, reliance on them to run the programme and recognition of their professional and human rights.
- In the Sonagachi Project, sex workers were not treated as passive ‘beneficiaries’ without any choice or agency but as change agents.

- In the early stages of the project, peer educators supported by the programme management, recognized that in order to realize even the very basic programme objectives of controlling transmission of HIV and STDs, it was crucial to view sex workers in their totality. They should be regarded as complete persons with a range of emotional and material needs and not merely in terms of their sexual behaviour. This holds true for sex workers but also applies to other target groups marginalised either because of their social exclusion per se or as a result of their vulnerability to HIV. The crucial first step in implementing any intervention programme for members of any marginalised population is to understand and address the range of issues that determine the quality of their lives and to locate these issues in the more general environment they are part of.
- In the Sonagachi Project, sex workers needs and interests were given prime importance in designing and carrying out any activity. The effectiveness and sustainability of any intervention programme depends on how the community for whom the programme is implemented perceives it as being beneficial to them. Thus, whatever the objective of the programme may be, it has to take into account and build on what the targeted community perceives as their immediate and urgent needs.
- The Sonagachi Project strongly emphasised the genuine and active participation of the sex workers at every level of the programme. Sex workers were given a central status within the programme right from the beginning. The leadership tried to imbue a genuine spirit of partnership between the project team and the community of sex workers they worked with. The real and dynamic involvement of members of the target community to effectuate the changes of the programme should bring about as opposed to the traditional approach of treating them as passive recipients of beneficence is crucial for ensuring effectiveness and sustainability of any programme.

(Jana et. al., 1999, p. 3)

## **Implementation**

The principles discussed earlier were put into practice through three principal activity components: working with the community, working controllers of the sex trade and advocacy to influence policy.

### *Working with the Community*

The project recognized the need for safe spaces both within the project and outside where members of the target community could confidently articulate their needs and aspirations. Sex workers are marginalised, socially excluded and discursively invisible. It is important to make their needs visible. The Sonagachi Project developed a relationship of trust between the programme management and the sex workers community through involving them in all aspects of planning and implementation in the project. Activities that directly addressed the needs articulated by sex workers were undertaken, even if they were not necessarily planned as part of the original programme. Activities like literacy, training and legal literacy training for sex workers were taken up. Immunisation and other support services for sex workers' children were also undertaken, like out-of-school education, sports, painting, cultural training etc. The sex workers' contribution to the programme and their role as members of the labour force were highlighted at local, national and international forums, thereby making them more visible as legitimate citizens, to instill a sense of pride and worthiness in them as sex workers. Steps were taken against all forms of discriminatory practices against sex workers, within the sex trade (like police harassment, violence, oppression by madams etc) and outside it (exclusion of their children from mainstream education, social stigma against sex workers etc). Various activities organised by the Project such as training for sex workers proved to increase the capacity of sex workers. This in turn helped to increase their self-esteem and empowered them socially, economically (by helping them to form their own credit society and social marketing agency) and politically (by facilitating the sex workers to combine and assert their rights and to help the formation of an exclusive platform of sex workers). The sex workers were employed as peer educators. The peer educators were provided with a uniform of green coats, and staff identity cards, which served to give them social recognition.

A total of sixty-five educators went from house to house in the red-light areas, equipped with information on STD/HIV prevention, AIDS, how to access medical care, and ways of questioning power structures that promoted violence (Madhu, 2000).

#### *Working with the Controllers of the Sex Trade*

The project acknowledged that the potential threat posed by controllers of the sex trade had to be neutralized through dialogue, negotiation and manoeuvring, so that the controllers did not impede the activities of the intervention programme. The Sonagachi Project accepted prostitution as a valid profession and no attempt was made at discouraging sex workers to practice prostitution and or at rescuing or rehabilitating them. This reassured the other stakeholders in the sex trade that ‘outsiders’ i.e. project workers were not going to disrupt their business. A thorough understanding of the sex trade, including the particularities of each red light area was developed to map the relation of power and conflicts in interests between different groups of stakeholders in the sex industry. Based on this understanding, specific strategies of maneuvering were evolved and followed to win friends and neutralize enemies within the sex trade. Special activities were targeted at different sections of the controllers of the sex trade. These included madams, pimps, babus (long-term regular clients), to orient them regarding the risk of transmission of STDs and HIV and also about the larger programme objectives to encourage them to work with the project rather than pose obstacles (Jana et. al, 1999). Peer educators conducted a survey with babus. Only 51.5% of the clients had heard of HIV/AIDS and 72.7% had never used a condom. As a result, alliances were formed to promote safer sexual practices including the elimination of sexual violence in the area.

#### *Advocacy to Influence Policy*

The project recognised the need for appropriate advocacy and lobbying to be carried out at the policy level, locally and globally, so that the legitimacy of the intervention programme be widely accepted. The project fulfilled this aim through extensive and on-going advocacy campaigns and individual lobbying with policy makers and opinion builders at all levels to persuade them of the legitimacy of the project’s approach and to convince them that sex workers are entitled to equal rights concerning health and life.

The following groups of people were targeted: local opinion makers, local elected representatives, ministers, political party officials, human rights and other democratic fronts, women's groups, trade unions, bureaucrats, intellectuals, other NGOs, bilateral and multilateral donor agencies and international HIV related networks. As a result, the Sonagachi Project gained public recognition and wide acceptance, which in turn gave the project the necessary maneuvering room to carry out the more radical options. This gave the project enough credibility as a programme to question and challenge some of the fundamental structural constraints that keep sex workers excluded from policy considerations and social participation, thereby rendering them more vulnerable to physical and social ill-being (Jana et. al., 1999).

### **Evaluation**

Evaluation was undertaken by project leaders using qualitative methods in eleven red light districts in Calcutta (Jana et. al., 1999). A total of 79 in-depth interviews were undertaken with brothel-based workers, floating sex workers, peer educators, DSMC members, project staff, pimps, madams, brothel managers and babus. Group meetings were also held with representatives from the police and the media. Project documents, media reports and police records were also documented.

The most notable achievement of the Project has been the establishment of Durbar Mahila Samanwya Committee (DMSC), which is a union for sex workers working together to promote and reinforce their rights. DMSC has recruited brothel based as well as floating sex workers from all the red light districts of Calcutta and other parts of West Bengal and has begun to establish branches in all areas where there are sex workers, in order to reach out their services to as many sex workers as possible. In recent times, the peer educators who formed DMSC have started operating a HIV help-line, mainly for helping serum positive sex workers and their families to cope with the social and psychological traumas associated with being HIV positive. When the workers come to know of sex workers who have contracted HIV, teams from the committee visit them in their locality to extend moral and material support and also to sensitise the whole community. This service not only helps the sex workers who may be infected but also serves to make people aware of the risk of HIV/AIDS. A group of male sex workers operating in and around the red light areas of Central Calcutta approached the DSMC and the STD HIV

Intervention Programme (SHIP) with a written petition demanding that they too be included in the Committee and the programme. SHIP and DMSC responded promptly and positively and the work now also responds to the needs of male sex workers.

The peer educators were also responsible for organising training sessions for police personnel. By the end of 1996, about 180 police officers had participated in the training programmes (Madhu, 2000). The project has been successful in responding to the needs of the community e.g. the project provided non-formal education when the demand for literacy arose as well as vocational training programmes for sex workers on security in old age. A credit and savings scheme was also established to help sex workers set up self-employment schemes. The sex workers set up the Komal Gandhar Theatre group. Through this group they have been able to communicate publicly, methods of negotiating safer sex with clients, pimps, the police and brothel owners in a non-threatening environment (Madhu, 2000).

Despite the success of the project, there were also a number of obstacles along the way. From within the sex trade, the greatest challenge was to instill a spirit of community among the sex workers themselves. However, the guiding principles of the project ensured that this issue was adequately addressed from the very beginning. The greatest obstacle was posed by the “dominant discourses on prostitution which threatens the very core of ‘respectable society’ (Network of Sex Work Projects, 2000). Public opinion of sex workers was that they could be pitied and rescued but could not be given respect as workers. They have to be bullied and coerced into protecting themselves against HIV, not given the autonomy or power to take control of their bodies and health. The Sonagachi Project recognizes that they have a long way to go and many battles to fight, before they can shift this deeply entrenched dominant ideology of sexuality and sexual morality and establish the right of sex workers’ to quality STD/HIV services and safe sexual health. Successful implementation of the project is not just about changing behaviour but also attitudes. Sex workers are vulnerable to HIV transmission not just because of their sex lives, but because they are not in a position to take decisions to protect their life and their health. Sex workers also face the barrier of being stigmatized as a result of their profession. Structural social rules exclude them materially and their stigmatisation adds to their material deprivation (Jana et. al., 1999).

The project has to continue to tackle the social and structural power relations and ideologies that put such communities in a vulnerable position in the first place. As Jana et. al., (1999) states:

“Given these conditions sex workers as a group will have to be enabled to break through the structural barriers that keep them excluded from access to resources as well as participation in society before any individual sex worker can be really empowered to protect herself”

(Jana et. al., 1999, p. 5)

The Sonagachi Project has been successful in tackling the health issues of the sex workers. Much of the project’s success lies in its innovative and flexible approach which has been found to have a far reaching impact not only on the lives of the sex workers but also on the community in general.

## **Overview**

The case studies presented highlight different examples of community health development initiatives. The projects tackle issues ranging from diabetes management to mental health to AIDS/HIV prevention and awareness. This illustrates the wide scope of a community development approach to tackling health inequalities. Each of the projects discussed share common community development principles i.e. participation, empowerment and collective action. Community development health initiatives have great potential to reduce health inequalities. The projects employ a bottom-up approach i.e. it involves the active participation of the community. The Green Paper ‘Supporting Voluntary Activity’ argues,

“It is important that action is built from the bottom-up and that action at the micro-neighbourhood level is supported and recognised by professionals, local authorities, health boards and government departments”

(Dept. of Social, Community and Family Affairs, 1997, p.41)

The issues dealt with e.g. mental health and diabetes, are issues, which traditionally would not have been tackled using a community development approach. Government policies are increasingly beginning to support a community development approach to health inequalities. This is vital for community development health initiatives in order to obtain the necessary resources for implementing a project. The evaluations from the projects studied, highlight the

valuable contribution community development can make to the health and wellbeing of various groups in different societies. A community development approach responds to the communities needs and so is flexible. This flexibility is one of its key strengths and is what makes the approach adaptable to diverse issues and to different communities.

## **Chapter 4**

### **Evaluating Community Health Development Initiatives**

#### **Introduction**

This chapter reviews the evidence concerning the effectiveness of community development approaches in tackling health inequalities. The range and diversity of evaluation approaches used are discussed together with the key findings from existing studies. A number of evaluations are examined in detail in order to highlight the methodologies employed when evaluating community health development initiatives. The implications of the findings for policy and practice are considered, drawing out their implications for the role that community development approaches can play in tackling health inequalities.

#### **Evaluation**

There is growing recognition of the need for health policies and practices to provide clear evidence about effectiveness. With the emphasis on evidence-based decision-making, an ability to provide a clear rationale for a community development approach and credible evidence of its effects will increase support and opportunities for its successful implementation. Evaluation research has a critical role to play in providing evidence of best practice and creating a knowledge base about how health improvements can be optimised and health inequalities successfully redressed. Springett and Young (2002) describe evaluation as being in essence, a process of learning from experience; “Evaluation at its best is a process of reflection whereby an assessment is made as to the value of certain actions in relation to projects, programmes or policies with a view to improvement “ (Springett and Young, 2002 p. 155). Therefore, meaningful and methodologically sound approaches to evaluation have an important role to play in supporting the efficacy of community development approaches in tackling health inequalities. As Billings (2000) points out, lack of clarity surrounding evaluation may lead to insufficient evidence of the most effective interventions and the nature of any health gain resulting from community development approaches. However, the complex nature of community development evaluation is also now widely acknowledged. Knowledge of the most suitable methods of evaluation is essential, not only to reveal the most effective and acceptable interventions, but also

to justify the value of community development to stakeholders with respect to future investment in this way of working.

In reviewing the evidence for the effectiveness of community development approaches and in particular in relation to tackling health inequalities, there is a paucity of systematic reviews in the area and the evidence that does exist is, in many cases, contained in unpublished reports. However, it should be noted that the lack of a systematic body of evidence in this area is not unique to community development approaches. The University of York (1995) carried out a review of the research on the effectiveness of health service interventions in reducing variations in health. The review examined some 94 studies meeting the inclusion criteria. Only interventions studies with an experimental or quasi-experimental design were included. Due to the diversity of interventions, settings, populations and outcomes, the authors report that a sensible quantitative synthesis of the results was not possible. A narrative review of individual studies was undertaken instead to highlight the characteristics of successful interventions. The findings highlighted the difficulty in attributing cause and effect from complex evaluations, which often entail a number of longitudinal, interpersonal and group interactions with people from deprived communities. This is particularly true when considering interventions, which use community development principles (NHS Centre for Research and Dissemination, 1995, p. 35). The Report suggests that a 'pluralistic' approach to evaluation is needed for this form of intervention, incorporating both qualitative and quantitative methods, as appropriate.

A number of key problems with the design and execution of evaluations were identified in the review. These difficulties included:

- A number of studies give only a limited description of the nature and content of the interventions used. This makes attempts to replicate the interventions difficult. In addition the methods used to recruit study subjects and numbers of subjects participating are not clearly reported.
- The sample sizes used are often too small, which reduces the power to detect differences as being statistically significant and so may not allow conclusions to be drawn about the effectiveness of interventions.

- Many evaluations were conducted without any attempt to identify a control group. This makes it difficult to attribute any change in the outcomes measured to the intervention.
- When a control group was included in the evaluations, many programmes failed to carry out and/or report baseline measurements. This makes it difficult to assess the comparability of the groups before the intervention was applied. Even in randomised studies, particularly the smaller ones, it cannot be assumed that intervention and control groups will necessarily be similar at baseline.
- Several studies used outcome measures, which were not particularly appropriate to the intervention being studied. For example, one of the studies undertook a randomised controlled trial to study the effects of home visits providing psychological support and advice on pregnancy to pregnant women. The outcomes measured included birth weight and the number of clinic visits, but no measures of maternal mental health were reported.
- The follow-up periods used were often too short to enable the potential value of an intervention to be assessed, or to assess whether short-term effects were sustained.

(NHS Centre for Research and Dissemination, 1995, p. 36)

Gunning-Schepers and Gepkens (1996) using the York Review and evaluated interventions in Holland, also noted a wide variation in evaluation methods used. Outcome measures across studies differed resulting in problems cross-comparing effectiveness. They also noted a lack of sophisticated tools that would enable measurement of long-term health outcomes resulting from health interventions. Both reviews acknowledged the difficulties in applying experimental designs to community projects and drawing clear conclusions based on the existing evidence.

In the general area of programme evaluation and specifically in health promotion, there is growing dissatisfaction with the uncritical acceptance of more traditional perspectives on establishing an 'evidence-based' approach (Chen,1995; Nutbeam,1999; Tones, 2000; McQueen, 2001). The unilateral imposition of a hierarchy of evidence approach is being questioned, particularly one which focuses almost exclusively on evaluation outcomes from randomised controlled trials (RCTs).

The need for a more flexible approach to documenting evidence has been highlighted, one which embraces the process of programme development and implementation as well as programme outcomes. This calls for an expansion of the current range of methodologies and analytical frameworks applied in programme evaluation and a widening of the evidence base to be more inclusive of the realities of practical applications on the ground. (Barry 2002) A continuum of approaches are required ranging from RCTs to more qualitative process-oriented methods. The challenge has been identified as using evaluation methods and approaches which are congruent with the principles of practice (Labonté & Robertson,1996), and which cross methodological boundaries and seek to evaluate initiatives in terms of their process and well as their outcomes (WHO European Working Group on Health Promotion Evaluation,1998).

Debates about appropriate methodology abound in community development project evaluation. There is a general consensus in the field that traditional evidence-based perspectives are too limited and limiting in scope and do not do justice to the richness and diversity of current practice in the area. The unsuitability of experimental designs in evaluating community health development initiatives, e.g. such as those employed in the large scale heart health community trials, is now widely acknowledged. The complexity of multifaceted community programmes presents a particular challenge in terms of programme evaluation both in terms of the methodologies applied and the role of the evaluator (Connell, Kubisch, Schorr and Weiss,1995). At a more general level, Gabriel (2000) points out that in the spirit of a community approach, evaluators must become partners with practitioners and the community in "... adapting their designs, assessment techniques and reporting strategies to fit the local context and needs"(p. 340). This calls for a movement away from traditional evaluation approaches to one characterised by partnership with key players in a manner now recognised as participatory and empowerment evaluation (Fetterman and Wandersman 1996). Israel et al. (1994) advocate employing a participatory action research approach in order to identify outcome and process goals and objectives that are consistent with the community empowerment concept. Participatory action research implies that community members are involved in all aspects of the programme action and research in a collaborative and reflective process.

Community programmes must take account of the needs of different stakeholders: community, funders, workers, health professionals etc. and utilise an evaluation design which can respond to their differing goals. The participation of communities in the evaluation process from the beginning through to the dissemination stage is also increasingly viewed as a key element in the empowering process. The evaluation also needs to address and capture the individuality of the specific contexts. Innovative and dynamic programmes require a continual flow of information from formative and process evaluation in order to be able to change course in pursuit of relevant goals and to react to changing circumstances.

As most community development projects are implemented at small-scale local levels, these initiatives lend themselves to process-oriented approaches and to evaluation informed largely by qualitative approaches. A preference for qualitative evaluation approaches predominates in the available literature. The use of more pluralistic evaluation methods are advocated that will reflect, and be congruent with, the principles of community practice. There are a number of alternative methodological approaches, which are increasingly used for this purpose. These include the use of the case study method in capturing the complexities of programme implementation in terms of the specifics of context, time and place. A range of approaches covering action research methods and participatory social research are also highlighted as having an important role to play in developing more collaborative forms of research inquiry. These approaches seek to actively engage the researcher with those most involved and affected by the research in the process of evidence gathering.

However, projects may also be required by funders to justify their continuation based on project outcomes, objectives met and targets reached. Evaluators may be asked to provide evidence of project success in quantitative terms. In such cases pragmatic solutions need to be found in the form of methodological triangulation involving the combination of quantitative and qualitative data in order to inform both process and outcome evaluation requirements. There are convincing arguments for the application of multiple methods and the need for analytic frameworks to integrate quantitative and qualitative methods in a meaningful way. There is increasing acceptance that contrasting and complementary perspectives and methods are needed to fill out the larger picture and to tap previously undocumented areas of knowledge and practice

## **Approaches to Evaluation**

There are a variety of suggested approaches to evaluating community development initiatives covering formative, process, summative, pluralistic and empowerment evaluation. The action research model has been highlighted as an appropriate research method particularly with regard to informing the process of project development, feeding in evaluation results in order to identify projects strengths and weaknesses so that mid-course corrective action may be taken.

Process evaluation takes on a particularly important role in the context of community development programmes, which typically constitute multi-faceted interventions implemented with diverse target populations in complex community settings. Capturing and documenting the realities of the process of programme planning and implementation plays a key role in interpreting the overall impact and outcomes of the programme. Community interventions require especially comprehensive process evaluation systems to track the process of implementation and ensure adequate documentation of a wide range of activities and procedures. Process evaluation draws mainly on qualitative methods, and case study designs that include observation, interviews and documentary analysis.

Summative evaluation, also referred to as outcome evaluation, focuses on outcomes and, seeks to establish if the stated objectives of the project have been achieved. These typically include surveys or measurement of health behaviour and health system related changes. However, focusing exclusively on outcomes runs the risk of neglecting the process of any intervention and therefore, an inability to identify why a project has succeeded or failed. For this reason, experimental designs are generally not regarded as appropriate for community development approaches, due to the diversity of community contexts and populations and the difficulties in ‘controlling’ all relevant influencing factors or variables. Due to the comprehensive nature of community initiatives, the use of indicators to detect shifts in behaviour and attitudes may not be comprehensive or sensitive enough to capture the essence of the processes involved.

Pluralistic evaluation which accumulates evidence for a variety of different sources and uses different research methods have proved useful in capturing the complexities of implementing and affecting change in community programmes.

These approaches are particularly useful where the project is dynamic and shifting. However, the use of mix methods also calls for clear view of how the different types of data will sit together so that they may be interpreted in a meaningful way.

Participatory approaches to evaluation are those which attempt to involve in an evaluation all who have a stake in its outcomes, with a view to taking action and effecting change (Springett, 2001). There is a recognition in this approach that if evaluation is going to be useful, different views have to be taken into consideration when deciding on the focus and design of the evaluation (Fawcett et al., 2001). In participatory evaluation the focus is on knowledge creation in the context of practice, to encourage the development of local learning and capacity building. This approach differs significantly for more traditional perspectives, it involves stakeholders in the research process, it integrates evaluation into project work and it is not outcome driven. The aim is to use the research to inform the change process and involves a self-generating process, which is seen as potentially empowering and encourages innovation and change. However, these approaches are not without their weaknesses. Springett and Young (2002) point out that participatory approaches can often lack rigour and without some structure provided by an external facilitator direction can be lost. There is also a danger of losing sight of the bigger picture while concentrating on the specifics of each project rather than looking at common themes and generic processes involved across projects. It is also critical with these approaches that a special effort is made to create a loop into policy structures and to inform decision-making leading to broader changes in the policy context.

### **Evaluating for Best Practice**

Evaluation may often be seen as a burden and as being associated with pressure from funding agencies to highlight value-for-money. However, evaluation is a worthwhile exercise to highlight effective practice in community development projects. Evaluating for good practice can enable a project to look at the successes of the programme, assess weaknesses and clarify what needs to be strengthened or changed (Pavee Point, 1995, p.26).

The Scottish Community Development Centre (SCDC) argue that evaluation should be conducted in accordance with the values and principles of community development:

“This means working with communities to develop a shared view about what community development interventions are there to do, how they are going to work towards that view with the resources the community has itself, or can bring in, and provide opportunities for community members to play a direct role in the process, and have ownership over the outcome”

[www.scdc.org.uk](http://www.scdc.org.uk)

The SCDC advocate that in a community development approach to evaluation, it is important to ensure that the approach contains elements of the following features:

- Evaluation should be integral to community development
- Evaluation is fundamental to empowerment of communities
- Evaluation is part of the learning organisation
- Community development has measurable outputs and outcomes
- Evaluation has to be a participative process in which the community are real partners
- The approach should be indicative, not prescriptive
- Community development, and its evaluation, should be considered at policy, programme and project levels

[www.scdc.org.uk](http://www.scdc.org.uk)

Beattie (1995) reviewed reports of community health development projects in the UK covering the period 1979-1990. The review revealed that a variety of evaluation styles and methods were being employed. The methods used ranged from narratives of project activities, to participatory evaluation, action research, practitioner-as researcher models, external independent evaluation, objectives-based evaluation and critical review by a panel of experts. The choice of methods was described as being influenced by factors such as accountability arrangements, purposes for which evaluation was being undertaken and the audiences to which findings were being directed. Many of the reports were bringing together what Beattie refers to as a ‘multiple-portfolio’ approach, combining different information relevant to the questions posed by the differing stakeholders in community projects.

Beattie describes an overall shift towards the use of more pluralistic evaluation methods which focus on, “the portrayal of people, places and processes through ethnographic and other kinds of description” (Beattie, 1997, p. 234). Beattie describes such pluralistic approaches as being in essence a dialogical process of enquiry, which challenge many of the taken-for-granted assumptions in traditional evaluation research. The appeal of pluralistic methods is described as being; that the method of research evaluation reflects many of the features of community development itself; emphasising process, working with people in a non-judgemental manner, sensitivity to local cultures, collecting and negotiating an agenda of concerns from the participants and keeping firmly in view such issues as who owns the evaluation data and what action should flow from the data.

Smart (1999), reviewing the strategies adopted in evaluating community health development initiatives in Scotland, also reports a bias towards the use of qualitative methods. Smart conducted documentary analysis and semi-structured interviews within 16 Scottish community development projects. The review focused on identifying the nature of the evaluation activity taking place and also examined the degree of negotiation between funders, managers, project workers and community activists prior to undertaking the evaluation research. Smart reports a predominance of process evaluation but also some impact evaluation being undertaken. Three distinct evaluation strategies were identified:

- assessment of whether the activities were meeting the needs of service users through process evaluation a continuing basis
- monitoring of activities undertaken and used in reports to funders
- larger evaluation of specific services such as counselling and befriending services

Even though evaluation was routinely undertaken in the majority of the 16 projects, Smart reports a lack of confidence in relation to the knowledge and skills required. The need for training and support in techniques were expressed, both from those with little and those with much community development experience. Lack of time and resources were also highlighted as imposing constraints on evaluation. Smart reports little evidence of prior negotiation between the various stakeholders in agreeing the evaluation agenda.

There was a call for funding bodies to understand the principles behind community development as this would influence the type of information being sought from evaluations. Despite these difficulties, Smart reports that the majority of projects was quite positive about evaluation and viewed evaluation as an important tool for learning. However, the need for dedicated support in terms of funding, skills and time to undertaking evaluation activities was clearly registered.

A meta-analysis by Kar et al., 1999 sought to identify and quantify the factors affecting the empowerment of women and mothers for health promotion. The meta-analysis brings together 40 case studies from diverse cultures, including both industrialised and less-industrialised countries, in which disadvantaged women had successfully initiated and led effective social action movements which empowered them and improved the quality of their communities. The health promotion studies ranged from Mother's Club in Korea, Women Against Gun Violence in the USA, Pueblos Jovenes Community Kitchen Movement in Peru, to Committee to Rescue our Health in Puerto Rico. The projects were analysed using the following dimensions: problem, impetus/leadership, macro-environment, methods used, partners/opponents and impact. The analysis identified seven methods most frequently used for empowerment:

- empowerment training and leadership development;
- media use, support and advocacy for policy and programme support;
- public education and participation for opinion and resource support;
- organising partnerships such as associations cooperative and unions for collective/group empowerment;
- work/job training and micro-enterprise for enhancing autonomy and internal locus of control;
- enabling service and assistance for essential opportunities and resources;
- rights protection and social action/reform through victim protection, legislative lobbying and social action litigation.

The authors report that the most important conclusion of the meta-analysis was that even the most disenfranchised and deprived women and mothers can and do lead successful social action movements that are self-empowering and significantly enhance the quality of life of their families and communities. They report that involvement in social action movements, regardless of their specific goals, methods used or outcomes, has strong empowering effects both in terms of enhancement of the woman's subjective well-being, self-esteem and self-efficacy and as a result, their quality of life and social status in the community.

An interesting study by Travers (1997) reports on involvement in a community research project as an empowering process. The research took place as part of a larger nutritional inequities project in Canada working with socially disadvantaged women and their families in a community drop-in centre. The study describes the developmental process of change and emancipatory education that took place as a result of participation in the groups. A total of 32 women participated and the research included participant observation, group interviews and meetings. Participation enabled women to initiate collective action for social change to reduce nutritional inequities. The empowerment process resulting from participation was characterized in terms of gains ranging from personal development through to political action. These included the following elements:

- Consciousness raising as cultural development – recognition of oppression by gender, race and class progressing to new ways of thinking about and relating to the social world
- Developing a social learning community – evolution of a group with a common sense of purpose. The women described themselves as a learning community.
- Economic development – researching inequities in pricing quality and services through to formation of a grassroots cooperative grocery enterprise.
- Political development - recognition that difficulties in adequate food were not rooted in personal inadequacy; the women wrote to political leaders, became involved in a grassroots poverty group and saved the community drop-in centre from closing.

Travers reports that the research process entailed enabling the women involved to analyse and reflect on their experiences in ways that explored the social roots of their problems.

Robinson and Elliott (2000) present the findings of a qualitative study of the factors affecting the use of community development approaches to heart health promotion in Ontario, Canada. The qualitative analysis, based on interviews with key informants across the voluntary and statutory sectors, reveals that the use of comprehensive community development approaches is limited and that community agencies typically employ elements of community development approaches such as community organization or community-based approaches, often in combination and adapted to suit local conditions. The resulting landscape of community development approaches is characterised by “ a continuum of collaborative practices indicating that no one type of community approach is appropriate for all initiatives and in all communities.” (p. 219)

However, they point out that there was little evaluation of these varied practices of community development across communities and there is a need to investigate the effectiveness of a variety of community approaches both in terms of process and outcome.

The differences in community practices observed in this review were thought to be related to the complexity of community contexts, levels and types of capacity, and the influence of particular facilitators and barriers. The commitment of staff, volunteers and community members is identified as the key facilitating factor for inter-agency collaboration. A willingness to collaborate, common goals, leadership and resource exchange were also found to be facilitating factors for joint community health promotion. In terms of the barriers affecting the use of community approaches, Robinson and Elliott (op cit.) note that a lack of understanding and capacity related to community development strongly influences implementation of such approaches. While elements of community development approaches were employed, frequently these did not entail the key features of collective ownership, citizen involvement and community empowerment. Other barriers to collaboration included; lack of human resources, the negative political and economic climate resulting in health cut backs and health agencies not seeing the value in community participation or not being comfortable giving up control. Differences in organisational philosophies and perceptions of agency roles were seen as interfering with joint action on health in communities. Community development approaches may also be seen as a

lengthy process, taking a long time before tangible results are evident. Importantly, they highlight that health may not be considered a high priority in communities relative to more immediate social and economic concerns. For example, heart health may be unlikely to be identified as a priority issue in disadvantaged communities. This point is a particularly important one, which may often be overlooked by health professionals, and may play an important role in determining the readiness of the community to engage in community health development work around specific health issues. Robinson and Elliott (2000) conclude that the use and usefulness of community development approaches remain poorly understood, despite an identified need to develop and disseminate knowledge of community development approaches for and to health practitioners.

### **Case Studies in Evaluation of Community Health Development Projects**

In this section a number of projects are examined in detail order to highlight the evaluations carried out on community health development initiatives. The evaluations are examined in terms of programme process and outcomes and the extent to which changes over time are attributable to the programme using the following guidelines:

- Programme Process: what is going on in the programme. How is the programme being implemented? What are the aims and objectives? Is the programme doing what it is supposed to do?
- Programme Outcomes: what are the consequences of the programme for its users? What do the clients/staff/observers think have been the differences?
- Attributing outcomes to the programme: are observed changes over time clearly attributable to the Programme?
- Have links between the programme processes and outcomes been clearly established.
- Explanations: are there clear explanations as to how and why the programme changes have come about?

Four different project evaluations have been selected to explore different approaches to project evaluation. The evaluations examine how the process aims and outcomes of community development programmes targeting health inequalities are achieved. Two projects, employing largely qualitative methods, are examined; the Sunshine Coast project in Australia which evaluates the participation of consumers and carers in the planning and delivery of mental health services, and the Community Action on Health project, based in Newcastle upon Tyne (UK), which examines through participatory action evaluation, community participation in decision-making about local primary care health services. The evaluation of a more discrete intervention based on community development principles, the Community Mothers Programme, is included by way of contrast to demonstrate the use of more traditional outcome evaluation of this highly successful programme. Finally, an example of a dual track evaluation, in the form of the national evaluation of the HAZs initiative in the UK, is examined to explore the possibilities of learning from across a number of projects through the use of a common evaluation approach.

### **Evaluation of Community Action on Health**

Community Action on Health is a community led initiative based on the principles of community development that aims to tackle inequalities in health by working with local people to support them address their health related issues and influence policy and service decision-making. Community Action on Health emerged from work, which first began in late 1994 when a range of community workers, GPs and academics began exploring mechanisms for improving the health services offered in Newcastle upon Tyne. The project operates in an area of social disadvantage with a significant black and ethnic minority population. The project has been evaluated twice in its lifetime, 1998 and 2000. It is proposed to discuss the most recent evaluation (Murtagh, 2002) in detail. In December 2000 an evaluation of Community Action on Health was commissioned. The evaluation adopted a stakeholder approach. The aim of the evaluation was to gain an understanding of Community Action on Health from the multiple perspectives of those involved both at system and local level.

The evaluation employed a model of participatory action evaluation in order to:

“Involve stakeholders in key decisions about the evaluation and to integrate action, change and research to enable the results of the evaluation to be acted on and thereby increase the relevance of the evaluation process”

(Murtagh, 2002, p. 18)

The objectives of the project incorporate both outcome and process components. The objectives include:

- Take action to reduce health inequalities
- Take action to influence the way local services are provided
- Support communities to define their own health agenda
- Support communities to work together to change inequalities in health, resources, and access to health and social care

Two key indicators were used to assess the project achievements:

- Outcome indicators - evidence that the project aims have been achieved were examined through the understandings of both community members and health care decision-makers that action has been taken and support has been given to tackle inequalities in health and influence decision-making.
- Process indicators - examine how action is supported and enacted through the understandings of all stakeholders about how the project works.

### Methodology

Community Action on Health workers were involved in the research design and implementation. Qualitative methods were employed in the evaluation, as they were deemed best suited to achieve an understanding of the activities and impact of Community Action on Health.

The aims of the evaluation were to:

- Gain an understanding of Community Action on Health from the multiple perspectives of those involved, both at system and local level.
- Gain an understanding of how well Community Action on Health meets its aims.
- Carry out research, which remains respectful of Community Action on Health as a strategy, its workers and participants.
- Conduct ethical research that is appropriate, rigorous and systematic.

(Murtagh, 2002, p. 78)

In order to achieve this, the evaluation employed Participatory Action Evaluation. Participatory Action Evaluation follows principles, which are similar to community development principles and are therefore most appropriate to an evaluation of Community Action on Health. Participatory Action Evaluation aims to:

- Involve stakeholders in key decisions including what to evaluate and how to measure it.
- Integrates action, change and research to enable the results of the evaluation to be acted on and thereby increase the relevance of the evaluation process.
- Builds capacity in communities and services by facilitating learning, increasing the knowledge base and encouraging empowerment.

(Murtagh, 2002, p. 79)

Community Action on Health recognised that in complex social settings it is not possible to attribute changes to any one factor or the work of any one organisation. Therefore, it is more valid to look at the perceptions of those whom the change is directed e.g. the community and service providers. The evaluation indicators looked at the following:

- Actions to reduce inequalities in health and influence the way local services are provided.
- Support communities to define their own health agenda and to work together to challenge inequalities in health, resources and access to health and social care.

A total of 36 key stakeholders were interviewed or took part in focus groups as part of the research. Stakeholders included community members, Community Action on Health workers, other community workers and health care decision-makers in statutory organisations. The interviews and focus groups were conducted at a time and venue suitable to stakeholders. All interviews and focus groups were recorded and later transcribed. The question guide consisted of open-ended questions, which enabled interviewees to elaborate on issues, which were relevant to them.

The data analysis was based on a thematic analysis of content. This involved the following four methods, triangulation (mixed-methods approach), member checking (i.e. is the analysis substantiated by the participants and does the analysis make sense to the participants?), open data reporting (the report as a means for the reader to evaluate the conclusions of the analysis) and group development of conclusions and recommendations. The results were presented thematically with representative quotes to demonstrate an emerging issue or theme.

### Key Findings

#### *Community Agendas, Community Voices: Using Community Development to Address Health Inequalities.*

Community Action on Health works from a community development approach. The community development model is identified as vital for developing meaningful community participation in decision-making. The project works from the community's agenda and not the agenda imposed by the government or other interests. Community Action on Health have supported and facilitated community voices, which adds relevance to the work of the project. It provides an opportunity to ensure that community needs are being met. As one community worker stated:

“It's not like the worker is saying what the community needs. It's the community itself saying 'that's what we want' and Community Action on Health tries to ensure if they don't have power if they don't have resources that at least it's a bottom to top approach. They're supporting the community wholeheartedly. It's not tokenistic.”

(Murtagh, 2002, p. 24)

Staff and senior management noted that the community are becoming more empowered and so, are better equipped to engage at the decision-making level. The communities are empowered to challenge current practices and do this in a constructive manner. The evaluation found that the perceptions of senior management of a more empowered population and of their own changing approach to community involvement is an indicator of their level of commitment and therefore the potential to shift power dynamics. Senior management who work with an understanding of accountability to an empowered population play a role in making the change towards such empowerment (Murtagh, 2002, p. 61). However, it was also noted that this process of empowering the community is still very much in its infancy and is limited by resources.

In relation to network building Community Action on Health view their role as facilitating links to enable relationships to be built between communities, individuals, community groups and agencies. The project recognises that relationships built on trust and good communication are a key part of the success of Community Action on Health. The evaluation found that while the project has been successful in creating linkages it also has the potential for conflict with other community groups in the field who may see Community Action on Health's approach "as poaching or encroaching on the work of other community workers" (Murtagh, 2002, p. 28). The networking element of Community Action on Health's work relies a great deal on the existence of community groups and other community workers. The advantage of such an approach ensures that the project can enhance existing work and seek to build trust between projects. However, if there are few community groups in the target area it can limit the amount of networking that is carried out. There is also a concern that the existing groups may be weak. Community Action on Health has adopted different ways of working with and supporting community groups. This flexibility ensures that the community's issues are dealt with in a manner, which is appropriate to them.

The evaluation identified the need to train community members to actively participate in decision-making arenas. The development of skills, knowledge and confidence are as important as direct participation. As one of the senior managers commented:

“If you want true people from the community to represent their communities they cannot be expected, no-one can be expected to understand the vast jargon that is used by public sector organisations. It disempowers people completely. If you are going to support people you have to give them maximum training, whatever they perceive their needs to be, to enable them to have the confidence to go forward and speak up. Because there is an awful lot of members of the public who won’t speak up. It has to get to a particular point before they’ll even attend meetings because they find them so daunting”

(Murtagh, 2002, p. 31)

Community Action on Health acknowledged the resource constraints between training community members and engaging in decision-making forums. The project still has a lot of work to do in relation to engaging communities and community groups. Community Action on Health identified the need to ensure an ongoing process of self-reflection in order to ensure the pertinence of their work. They acknowledged the fact that there will always be a tension between the concept of community representation and community voices when workers are engaged in the process of enabling communities to become active in decision-making processes. The project is aware of this tension and so, seeks to avoid talking on behalf of community members where communities can talk for themselves. The evaluation made the workers aware of the fact that there is a potential risk for Community Action on Health to become an alternative for community voices as some agencies may talk to the community workers as a shortcut.

Tackling health inequalities in health are a key priority for Community Action on Health. In relation to tackling health inequalities, a member of the community made the following comment:

“Community Action on Health provides a real opportunity to provide a cornerstone on tackling health and inequalities in this city. It is a vital organisation to do that. It is probably nearer to true community involvement and power sharing with the community in terms of health than a lot of other organisations.

(Murtagh, 2002, p. 45)

The impact of the project's work was described as coming in various different forms e.g. changes in service delivery, direct responses to specific issues, changed attitudes and understandings of health inequalities. However, the precise nature of such changes are not documented in detail. Community Action on Health has facilitated community involvement and as a result has led to a shift in power. Capacity building has been vital for bringing about changes in health and other government agencies to tackle inequalities in health. Another key strength is the project's networking approach with its work across community, statutory and non-statutory agencies. Networking and partnership facilitates understanding and thereby supports change.

Community Action on Health has been found to be successful in tackling discrimination. Black workers described the trust and credibility of the work of Community Action on Health related to racial discrimination and health issues for minority ethnic communities.

The support from the Labour Government in 1997 was noted as particularly important for the success of the project. The Government made a commitment to tackle health inequalities and Community Action on Health were well placed to carry out this task. One community worker made the following comment in relation to the role of the Labour Government:

“I think the strength of Community Action on Health came at the right time, at an opportune moment. The Labour Government coming into power with that agenda around addressing inequalities: it was well placed at that point. I think decision makers could not ignore what Community Action on Health was saying. But also Community Action on Health was extremely effective at raising [inequalities]with key decision makers. I think it was very successful that changing people's ideas and opinions around it, at chief executive levels”

(Murtagh, 2002, p. 51)

The evaluation identified that key to the success of the project was the positioning of health inequalities as a key framework for its work, its effectiveness in raising the issue of health inequalities with various groups and the acknowledged power to tackle discrimination.

The effectiveness of the approach is attributed to the trust built and the methods of working used by the project. The facilitation of partnerships have had a demonstrable impact including

increasing understanding among senior managers of the day to day impact of inequalities on people's lives. Senior managers describe the projects' focus on tackling inequalities as one of the key strengths. The combination of methods used, a wide network and an agenda driven by the community themselves enables meaningful dialogue between agencies and the communities in a way that other mechanisms for public involvement do not. Likewise, the development of skills and capacity within the community is an important outcome of the approach. In conclusion, the evaluation highlighted the fact that Community Action on Health is a well respected and well supported organisation, both for its way of working to maintain a focus on communities and their agendas and its ability to provide a conduit between communities and decision-makers in statutory authorities

(Murtagh, 2002, p.72).

The evaluation did however, also highlight a number of weaknesses in the project. The project reflected on the necessity for balancing challenge and co-operation with the system because there is always a danger of becoming too comfortable within the system and therefore being co-opted by it (Murtagh, 2002, p. 60). In relation to raising community agendas, it was acknowledged that participation in decision-making takes work to establish and maintain. Community Action on Health has been successful in enabling people's voices to be heard but there are still members of the community who go unheard.

The evaluation approach is primarily process-oriented, examining through the perceptions and understandings of those who have contact with Community Action on Health, how the project aims are achieved and where future attention is needed. Murtagh (2002) acknowledges that changes in policy and practice are complex processes attributable to multiple causes and that the determination of change can only be made after a passage of time. However, this raises the issue of how to accurately evaluate this process of change over time. In this respect, the project evaluation needs to address two key questions which are highlighted in the report: whether any change has occurred in the existence of inequalities in health and whether public involvement has become a genuine and routine part of public policy and decision-making.

Murtagh acknowledges the complexity of these questions and suggests that these changes can only be determined in retrospect. However, it is not clear that any baseline information on these

issues is being collected or indeed being monitored over time. Murtagh's evaluation focuses almost exclusively on the perceptions of those to whom change is directed, i.e. the perceptions of those in the communities who are to be involved in decision-making and the perceptions of community service providers and service managers. An evaluation based primarily on perceptions is open to challenges as to whether perceptions are the most valid assessment of change and public involvement. For example, the key evidence of successful public involvement is the perception of community members that they have been involved. However, the report acknowledges that understandings of public involvement and participation are likely to differ considerably. Such an evaluation is open to question as to whether the elicited perceptions of 36 interviewees are indeed sufficient to convince those, who may need to be convinced, of the success of this project and whether the extent of the changes that have taken place are indeed fully captured through this evaluation approach. The complex issue of selecting suitable measures or indicators of project success is raised in this evaluation study.

Despite these methodological difficulties, Crowley et al. (2002) highlight that the project does provide evidence that community development approaches can be successful involving a wide range of people in discussions about local health services, including people with disabilities who are commonly excluded from citizen participation. They identified a key strength of the model as being the partnership built between the decision making and the communities that is described as having the potential to address the complexities of health and health inequalities. Drawing out the implications for best practice, Crowley (2000) outlines the following principles:

- The community is an asset and part of the solution – not a problem. Health regeneration of communities must be built on the skills of local people and communities.
- Community representatives need support to link to the wider community and community development input must be accountable to the local community and not the health service.
- Any approach must involve marginalised minority groups – people with sensory or physical disability, lesbians and gay men, the Black community etc.
- Financial support is necessary to ensure access – crèche, carer support, interpretation (incl. Sign language), translation and audiotapes etc.

- Community participation strategies are required where the community can set the agenda and raise the issues of concern to them.
- To involve the public, health decision-making bodies need to be developed so as to be responsive to the community's view.
- The process is important but if the community do not start to see some concrete outcomes for their voluntary involvement they will lose interest.
- If meetings include local people they must be conducted to ensure their participation and avoid jargon

(Crowley, 2000, p.7)

## **Queensland Mental Health Community Development Projects, Australia**

### Background

The Queensland Mental Community Development Strategy was funded and implemented in response to the Australian National Mental Health Policy (1992) which highlighted the importance of mental health as an important issue for the Australian public. The strategy is based on a community development approach, which is defined as the “development and utilisation of a set of ongoing structures which eventually allow a community to meet its own needs” (Bush et al., 1998, p. 1). The key priorities of the strategy include the following:

- To involve consumers and carers in the planning, operation and evaluation of services.
- To improve intersectoral links between mental health services and other services so as a wide range of support services can be accessed, particularly housing and disability services.

(Bush et al., 1998, p. 1)

The strategy argues that a community development approach is important because consumers and carers become more empowered when they have the opportunity to participate in the planning, implementation, delivery and evaluation of mental health services.

Furthermore, a consumer-focused approach improves the potential for mental health services to address the needs of consumers and carers. As a result of the strategy, a number of Mental

Health Community Development Projects have been funded and implemented. Each of the projects, while funded under a set of overall statewide objectives is unique to the setting and community in which each currently operates. The overall framework of the Mental Health Community Development Projects is based on community empowerment and participation. The objectives of the Projects are identified as follows:

- Identifying the needs of consumers and carers;
- Promoting the development of intersectoral links with government and non-government and community agencies to meet the needs of the community;
- Improving participation of consumers and carers in the process;
- Promoting public awareness of mental illness through community education programmes;
- Promoting service development;
- Facilitating access to services through providing information, education and training for service providers.

(Bush et. al., 1998, p. 3)

Each of the projects have been evaluated in order to determine the effectiveness of each individual project within its own setting and district. The purpose of the evaluation was to determine:

- The extent to which each project has met the original state-wide objectives.
- The extent to which each project has met local needs as defined by needs analysis and population based mental health data.
- The extent of sustainability of the responses developed by each project.
- The cost of the project (directly funded and indirect) against the utility of a co-ordinated community response.
- The extent to which each project has demonstrated innovations.
- The nature of the projects by providing a broad-based commentary.

(Bush et al., 1998, p. 3)

The evaluation was based on qualitative information collected during short-term visits to each of the project sites. No baseline information was available. A process of triangulation was used to

develop consensus concerning the information collected during the evaluation. The evaluation involved post-intervention semi-structured interviews with a sample of key stakeholders. Interviewees included the community development workers, management committee or workers from the supporting organisation, consumers, carers, director of the District Mental Health Services or nominee and other key service providers. Each of the projects were visited and a rapid appraisal process was used to collect information. The appraisal comprised of two elements (1) the collection of any reports or profiles of each of the projects and (2) interviews with a selection of stakeholders. In addition, an evaluation project review team was established in order to provide comments at critical stages during the process.

The community development workers organised the interviews. The interviews were conducted face-to-face, however, in some cases it was necessary to carry out phone interviews due to the remote location of some of the projects. Two members of the evaluation team conducted the interviews. The evaluation considered a number of key factors, which were used as measures for evaluating the projects, including:

- The community environment in which each local project operates;
- Each project's community development framework;
- The District Mental Health Services' attitudes to the role of each project and the role of consumers, carers and the non-government sector;
- The roles of community development workers as distinct from the District Mental Health Service Staff;
- The impact of any structural changes on the project, including Government policy, changes in staff and funding cycles.

A set of universal questions was posed to the projects, which covered topics such as approach of the project, extent of consumer participation, impact of consumer participation and activities undertaken.

Specific questions were developed to obtain information from each of the stakeholders. At the end of each site visit, an open feedback session was held at which initial findings of the site visit were fed back to the participants for verification and further discussion.

It is proposed to discuss one of the evaluations – the Sunshine Coast Project, in order to highlight the evaluation process in more detail.

### The Sunshine Coast Project

The Sunshine Coast Mental Health Project began in October 1994. The project has a well-articulated model of community development that links the State-wide objectives with well-recognised processes of capacity building. The model embraces the need for change within the agencies and organisations accessed by those with a mental illness as well as personal growth of those with a mental illness.

The Sunshine Coast is a densely populated area, which consists of a local population base as well as a high number of tourists. The Sunshine Coast has a relatively small population of people from Aboriginal and Torres Strait backgrounds (1%). The population of people from non-English speaking backgrounds make up 17% of the population and according to the community needs assessment carried out by the project, people of non-English speaking backgrounds tend to have well-established networks and a strong sense of their own community (Bush et al., 1998, p. 82). The Mental Health and Wellbeing profile of Adults: Australia estimated that approximately 22,400 people aged 18 years and over will experience a significant disruption to their mental well-being during any 12 month period in the Sunshine Coast area (Cited in Bush et al., 1998, p. 83). The Sunshine Coast Project recognises that in order to have the capability to provide for such a large group, it is necessary that there be support from government, non-government and community organisations.

## Key Findings from the Evaluation

### *Achievements of the Sunshine Coast Project*

From the early stages, the project has been successful in building consumer and carer involvement from a comprehensive needs assessment. In the first year an ongoing focus group was established which advocates for and acts on behalf of mental health consumers. This initiative has led to considerable opportunities to empower, and increase the skills of consumers and carers. There has been evidence of a net-widening effect in consumer advocacy and self-help beyond the local area and as a result, various other consumer groups have been established e.g. 'Sail Through Life' is a project which targets people who have a disability and gives them an opportunity to obtain a sense of independence and control through the experience of learning to sail (Bush et. Al, 1998, p. 85).

### *Meeting the State-wide objectives*

To what extent have the service needs of consumers and carers been identified?

A needs assessment was carried out in 1995 by independent researchers, which looked at the community history, demographics, non-government and health services and basic mental health epidemiology of the area. A total of 30 participants from community organisations and groups were identified and consulted for the needs assessment. The aim of the assessment was to provide direction for the programme and to guide the nature of activities in the community. Needs assessment it is argued is an integral aspect of a community development approach in the project. Feedback has been an extremely important element of the project and as a result has been built into daily practice,

### *Intersectoral Links*

The needs of the community have been promoted in partnership with a wide range of organisations and groups. This has resulted in the an expanded community-based mental health network, resourced by a directory of services, which is widely disseminated (Bush et al., 1998, p. 87). The network has helped to build links between government and non-government services. This has led to a more co-ordinated response to mental health issues on the Sunshine Coast.

### *Extent of Consumer and Carer Involvement*

The history of the area highlighted strong discontent, resistance and tokenism when it came to consumer involvement in service planning, development and delivery. The evaluation found that this had changed as a result of the work of the project. Within the project, consumers are responsible for the direction of the work and have 50% voting rights on the management committee. The community development workers recognise that consumers need to be encouraged to be self-reliant and empowered. The evaluation noted an increase in consumer involvement in service planning, development and delivery e.g. the focus group was developed and initiated by consumers and is an independent action group.

### *Promotion of mental health awareness*

The project has been successful in working with a variety of community organisations to promote public awareness of mental health. This has contributed to fostering positive attitudes about mental health. A number of activities were organised. Examples of these activities include the following:

- Consumer talks on radio programmes on mental health segments
- Consumers trained to be radio announcers
- Television interviews regarding stigma and mental health
- Consumer and community development worker guest lectures at the local university
- Stress management workshops
- Library leaflets and displays
- Art competitions
- Mental Health Service Directory
- Shopping Centre displays

(Bush et. al., 1998, p. 90)

### *Has access to and development of new and existing services been advanced?*

The project was found to have had its greatest success in stimulating the establishment and maintenance of consumer self-help and support groups and in contributing to change in existing organisations and the Mental Health Service.

The groups which have been established appear to have a great deal of sustainability due to the fact that they have limited reliance on the projects resources and a great deal of consumer participation. The project has also linked into other groups and organisations which has helped improve access to services.

Have service providers received information, education and training in mental health issues and strategies for working with consumers?

Consumers have been involved in training the Division of General Practice in the Sunshine Coast area. Initially, there was resistance but gradually over time, the training has increased the potential for service providers to become more aware of their attitudes towards mental health consumers. The community development workers have also provided training to various projects and groups in the area.

### *Capacity and Sustainability of the Sunshine Coast Project*

#### *Building partnerships*

The evaluation demonstrated that the project has the capacity to identify organisations and groups to run a variety of projects that enhance consumer needs. The project identified three types of partnership. First, it has used partnership principles to support consumer self-help and advocacy groups in such a way that these are consumer led rather than project reliant. Second, it has built partnerships with other local health and welfare organisations to deliver projects such as National Mental Health Week activities. Third, it has maintained links with the Mental Health Service during a period of rapid change during which the service has moved toward a more consumer-orientated approach (Bush et al., 1998, p. 91). The project evaluation highlighted a strong sense of trust and mutual obligation between the project and many consumers and carers.

#### *Knowledge transfer about mental health between the partners*

The project has used a variety of methods to transfer knowledge including training courses, use of consumers in awareness raising activities and committee work. The approaches used could be strengthened with ongoing training for consumers.

The evaluation found that there is evidence to suggest that the involvement of consumers in the quality and management of the Mental Health Service is beginning to change the services operations although this will need continued monitoring.

#### Increased ability to problem solve between the partners

Bush et al. (1998) argue that a change in funding organisation, community development workers and premises has not had a negative effect on the projects progress because good team work principles and negotiating skills have been applied. The project has become a role model for others and has demonstrated how to best apply community development principles to a mental health project. As Bush et al. (1998) state:

“There is evidence of both durability and flexibility in the project’s activities, which rest on advanced problem solving, mutual trust and obligation”

(Bush et al., 1998, p. 91).

#### *Economic capital between partners*

The project needs to identify its costs and benefits to the local community and to make this a priority for the future. There is also a need to strengthen financial investment of public and private organisations, which in turn could further increase the sustainability of the Sunshine Coast Project. The project has already attempted to put this into action, through local sponsorship of events and local government funding of some activities e.g. funding was received from a Community Benefit Fund for printing an information booklet.

#### Human capital between partners

One of the main strengths of the projects has been the significant increase in consumer and carer empowerment through gaining experience in the running of local projects. Bush et. al. (1998) state “this substantial investment would appear to provide benefits to the restructure of the mental health services”

(Bush et. al., 1998, p. 92).

### *Social capital between partners*

There is a great deal of respect between the consumers, carers and the project due to their willingness to work together in partnership. This respect has spilled over into many of the activities in which the project is involved.

### *Barriers for the Sunshine Coast Project*

The stakeholders identified a number of barriers to the success of the project. Funding was identified as a barrier, in particular the short-term nature of funding and the uncertainty of whether the project will receive funding in the future. The level of consumer involvement in the project has been hampered by distance and travel. The evaluation also found that the large amount of distinct and different communities in the area has proven to be a barrier to the work of the project. This has made it difficult for the project to cater to the needs of all the population in the region.

Based on the evaluation, it was concluded that the community development approach has resulted in the participation of consumers and carers in the planning and delivery of services in the area. The project successfully utilised the formal links between the mental health services and non-government services in order to effectively meet the needs of a diverse group of consumers (Bush et. al., 1998, p. 92). The networking approach adopted was seen as an effective way of increasing access to resources for consumers and carers. The project demonstrated how a community development approach can be used in mental health to advance the rights of consumers through individual participation and system brokerage. The Sunshine Coast Project was identified as a potential role model for similar projects in the future.

In terms of the overall Mental Health Community Development Strategy, this initiative is unique in the Australian context. Community development is a relatively unexplored approach to mental health among those with chronic and long-term mental health problems, who often experience marginalisation in the communities in which they live and have difficulties in asserting their rights in mental health services. These innovative projects demonstrate the value of a community development approach and its potential in the reform of mental health services and asserting the rights of service users.

The projects signal a clear shift in focus from a clinical to a social model of mental health. The readiness of local mental health services and other community organisations to embrace the objectives of the projects and the community development approach is seen as key factor in influencing the reform of the mental health services and partnership building in the community. Variation in readiness across the projects was also identified as affecting the time it takes to reach desirable outcomes.

In terms of providing evidence of the success of a community development approach, a number of weaknesses are identified in the overall evaluation process across the nine projects. These limitations were summarised as follows by Bush et al., 1998:

- There were considerable time constraints on the evaluation to meet the deadline imposed by Queensland Health. Subsequently, a limited number of stakeholders could participate in the evaluation interviews.
- There is variation in the extent of needs assessment initially undertaken when projects were established.
- There was variation in the methods that has been used for project reporting. The evaluation team planned to review the existing reports to determine the processes undertaken to meet the State-wide programme objectives. There was considerable difficulty in obtaining these reports.
- There was no baseline data upon which to compare changes over time. The evaluation team attempted to document changes in consumers and carers' lives with their retrospective views on local conditions prior to project implementation.

- No standardised methods have been applied to determine the strengthening of local community organisations and groups to support those individuals experiencing mental ill-health
- There is no data available for cost and benefit analysis. The evaluation examines the cost per project against the utilisation of locally co-ordinated community organisation by using a descriptive account of achievements.

The evaluation points to the fact that as the projects develop, mechanisms to ensure accountability, quality practice and observable gains in mental health will need to be devised. It is interesting to note in this respect that standardised indicators are recommended in order to determine the benefits of community development strategies in mental health. The need for both process and outcome indicators is highlighted including; the extent to which mental health users participate in quality improvements in mental health services; the readiness of services to involve consumers in quality improvements; the outcomes of mental health promotion through partnership building with the community sector; the reduction of individual and environmental risks to mental health and the improvements in access to services as a means to early intervention.

### **The Community Mothers Programme – Dublin**

The Community Mothers Programme is a parent support programme for first-time and second-time parents of children aged from 0-24 months living in disadvantaged areas. This programme may best be described as a community-based project which applies community development principles. The original Community Mothers Programme began in Dublin in 1988 and was based on the Bristol Child Development Programme in which health visitors and public health nurses were involved in delivering a specially designed child development programme (HEA, 1998, p. 59). The Community Mothers programme evolved from this model in Ireland but due to lack of resources it was decided to recruit non-professionals in the form of successful experienced mothers to implement the programme instead of health professionals. The Dublin programme focuses on health care, nutritional improvement and overall child development. The programme has been adopted internationally.

Experienced mothers, known as community mothers, are recruited as volunteers and trained to give support, and encouragement to parents in rearing their own children. The volunteers are recruited from the same area as the programme recipients. The community mother works under the guidance of a Family Development Nurse (FDN), a trained public health nurse whose role is to serve as a facilitator, guide, resource person, confidante and monitor for the programme. The model is described as “ one of parent enablement and empowerment such that parents learn to cope with the problems of child rearing and to find as far as possible their own solutions to problems, thus reducing their dependence on professionals” (Johnson and Molloy, 1995, p. 74).

The model used is described as being based on the philosophy of Alma Ata (WHO 1978) with its emphasis on self-care “ It is based on the concepts of partnership and empowerment, promoting participation of clients and individual and community self-reliance” (Johnson and Molloy, 1995 p. 76).

This approach is outlined by the authors as follows;

- Drawing out the potential of parents rather than giving advice and direction
- Using a behavioural approach in which parents are encouraged to undertake agreed tasks
- Using illustrated cartoon sequences to shown the alternatives available to parents in coping with various child rearing problems.

The training and education process for the FDNs seeks to engender this approach through fostering a move from a more traditional helping approach to one based on facilitation and participatory management. The role of the programme co-ordinator is to provide specialist support, education and management in the implementation, maintenance and development of the programmes (Molloy, 1993). The coordinator’s role is to assist the FDNs and the community mothers in a process of mutual learning. Supervision within the programme is done through regular evaluation and a process of reflection.

### Programme Implementation

The community mother is placed with a number of programme families. Each FDN tries to recruit and support up to 20 mothers at a time. Each community mother attempts to support between five and 15 first-time parents and meets with the FDN once a month for review sessions to discuss programme work with families and any problems encountered. Every two months the community mothers in an area meet as a group where common problems are discussed and ideas exchanged. There is also a skill development aspect to these meetings whereby listening skills, problem solving and group facilitation skills are practiced. The community mothers attempt to visit first-time parents for one hour each month, by appointment, up to the child's first birthday. The parent is recognised as an equal by the community mother and as expert in reading her own child. The community mothers aim to support the parents in achieving their own goals using a non-directive approach. The relationship sought between the community mother and the parent is one of mutual respect. The monthly visit to the family is the main focus of the programme. The issues discussed during the visit are tailored to the needs of the individual family and the approach is supportive of parents' own ideas and respects each parent's desire to do what is best for the child.

### Programme Evaluation

An evaluation of the programme was carried out by Johnson, Howell and Molloy (1993). Employing a randomised controlled study, 262 mother and infant pairs who lived in deprived areas of Dublin were randomly allocated to the intervention (N=114) and control group (N=121). A total of thirty experienced mothers from the same community were recruited as community mothers. All the first time mothers received standard support from the public health nurse. In addition those in the intervention group received the services of a community mother, who was scheduled to visit monthly during the first year of the child's life. At evaluation at the time of the child's first birthday 232 pairs (89%) had completed the study (127 in the intervention and 105 controls).

Both group shared similar demographic profiles. At the end of the study children in the intervention group were more likely to have received all of their primary immunisations (85% intervention versus 65% in the controls), to be read to (98% intervention group versus 54% controls), and to be read to daily. Scores for stimulating the child using cognitive games and nursery rhymes were also significantly better in the intervention group. They were less likely to begin cow's milk before 26 weeks and had more appropriate dietary intake. Mothers in the intervention group also had a better diet than that of the control group. Maternal self-esteem indicators were also better i.e. they were less likely to be tired, feel miserable, and want to stay indoors. Intervention mothers also had higher scores for more positive maternal feelings and were less likely to display negative feelings. The authors concluded that that “ the empowerment approach to promoting parenting skills is sound, practical and effective”. The programme can be delivered effectively by non-professionals, themselves mothers living in disadvantaged areas. The cost-effectiveness of this programme was also highlighted in terms of future developments. In 1991 the programme had an overall budget of £50,000 which covered the salaries of 11 FDNs, a clerical assistant, and a £2 per visit paid to the community mother and other non-remunerative items. Throughout 1991, 130 community mothers visited between 900 and 100 first time parents. A seven year follow-up was also carried out by Johnson, Molloy, et al. (1995) which supports these initial findings.

The programme has been widely replicated including an initiative with the Traveller community in Ireland (Fitzpatrick, Molloy and Johnson, 1997, p. 300) where programme visits from community mothers were developed, with 70 Traveller families a year having monthly programme visits from experienced community mothers. The Community Mothers programme has gained an international reputation and various models are in operation across Ireland, the Netherlands, the UK, Australia and USA. Replications include the Thurrock Community Mothers Project and the Mothers Inform Mothers Programme in the Netherlands, both of which have also been evaluated and provide supportive findings of the effectiveness of this model of promoting positive parenting. A bi-product of the programme is a reduction in child abuse and reduction of isolation and depression among mothers (Mental Health Europe, 2000, p.112).

The evaluation in the Netherlands also shows the effect on the Community Mothers who develop their own self-esteem, report a high level of satisfaction and tend to find a paid job after the project. The Irish evaluation also shows that many of the Community Mothers become involved in adult education programmes such as literacy, counselling and personal development programmes, as a result of their contact with the programme demonstrating welcome a spin-off from the process of empowerment.

A process evaluation of the Essex Programme was carried out in 1992, focusing on changes and adjustments over six months of the project. Three sets of data were obtained in order to represent the views of the different project participants (Suppiah, 1994, p. 51). Families involved in the project commented that they had been helped in a number of ways, including feeling less isolated, help with children's sleep problems, ideas for games and toys and help with coping with children's behaviour. The evaluation found that community mothers benefit from joining the community mothers' team and develop an increased appreciation of their own family, the value of being a mother and further their knowledge and understanding of the local community. The Essex Community Mothers Programme has won a Regional Child Protection Award and a Regional Healthy Alliances Award (HEA, 1998, p. 63). The findings from the evaluation undertaken by the Community Mothers Programme in Thurrock found that the programme addressed inequalities by improving the health and development of young children through work with their parents. The findings highlighted include the following:

- Reduced isolation/depression in mothers
- Raised maternal self-esteem/confidence and positive feelings
- Improvements to child behaviour difficulties
- Improved cognitive stimulation of children
- Improved appropriate access to services e.g. health, parenting, training
- Volunteer skills development and increased access to employment opportunities
- Improved maternal and child nutrition
- Increased immunisation uptake
- Improved speech development
- Improved safety awareness

The findings of an evaluation of the programme in Wigan and Bolton Health Authority have been quite similar to the successes of other Community Mothers Programmes elsewhere. The evaluation did acknowledge that community development initiatives take at least two years to begin to be accepted in communities. They cautioned that funding agencies may expect results too quickly and that it may not be possible to prove success for a number of years. The programme also noted the importance of networking with other people working on similar initiatives in order to learn how others have overcome obstacles ([www.had-online.org](http://www.had-online.org)).

The Community Mothers programme is widely recognised as having the potential to be applied across different communities with relatively few adaptations to programme structure and materials used. It is a low maintenance, low cost and highly effective programme which promotes parenting skills and child development in disadvantaged communities employing a community empowerment approach.

While the Community Mothers programme may not strictly be described as a community development project, it is based on empowerment principles and contains a number of interesting features, which highlight its potential role as part of a more comprehensive community development approach in tackling inequalities in the area of child development. The enabling and empowering approach used is one of the unique features of this programme and makes the programme very suited to delivery in disadvantaged community settings. This is essentially a peer-support programme which values the experiential knowledge of experienced mothers and also avoids any negative labelling that may be associated with receiving professional support in child rearing. These are important considerations in the delivery of accessible community initiatives for disadvantaged groups. Community mothers live in the locality, once recruited the community mother undergoes training, during which the concepts of the programme are explained. Community mothers meet regularly and exchange ideas and explore ways of delivering the programme. It has the capacity to serve as a self-generating programme whereby mothers who have themselves been recipients of the programme go on to become community mothers, thereby developing the model through a cascade effect. In addition to the direct impacts of the programme on the child's development and mother's mental health, the programme developers also note that contact with the programme has empowering effects for

both community mothers and participating parents leading to further education, personal development and employment opportunities. The strong evaluation findings and the clear impacts and outcomes of the programme also add weight and support to the value of the programme. The more traditional outcome focused approach to programme evaluation in this respect stands in contrast to the other two projects that were reviewed which relied almost exclusively on process-oriented assessments.

Clearly, this is a more discrete programme with a narrower and more specific focus and lends itself to more structured traditional evaluation approaches. However, process evaluations have also been conducted across the various replication sites. The value of a clear underpinning programme philosophy or theory leading to demonstrable project impacts adds weight to the programme's success and has clearly enhanced support for the widespread adoption of the programme internationally. That said, the strength of the findings have not guaranteed prioritisation or sustained funding of the programme as an example of best practice on a national level in Ireland, the home place of its development.

### **Evaluation of Health Action Zone Initiative in the UK**

One of the underpinning principles of the Health Action Zone (HAZ) initiative, already described in Chapter 3, is that they would take an evidence-based approach and would constitute 'learning organisations' that would inform policy and practice. The UK Department of Health commissioned a national evaluation early in the lifetime of the HAZs and also emphasised the importance of more local evaluation efforts. Employing this dual track approach, the national evaluation was intended to address strategic issues of importance for central policy on HAZs and also inform the wider policy agenda. The overarching aim of the national evaluation is described by Bauld and Judge (2002) as being; "to identify and assess the conditions in which strategies to create a more substantial capacity for local collaboration result in the adoption of change mechanisms that lead to the modernisation of services and a reduction in health inequalities" (p. 9).

This aim is being addressed through the monitoring and mapping of all 26 HAZs, and through detailed investigation of the change process in a selection of HAZs. The work is being conducted by researchers at the University of Glasgow, the University of Birmingham and Queen Mary, University of London. The monitoring provides a basic description of overall change strategies, the way in which these develop and that progress that is made by HAZ within the three years of evaluation. Three separate groupings of case studies are also being developed to allow for more detailed investigation of individual projects; 1) examining the process of change at a strategic level, 2) strategies for building capacity for collaboration and 3) a focus on specific interventions aimed at tackling inequalities. In addition, each individual HAZ undertakes its own local project evaluation and a diversity of approaches are adopted across the different HAZs in keeping with their own specific project focus. A key mechanism for sharing the learning emerging from the evaluation efforts is the Local/National HAZ Evaluation Network which is maintained by the national evaluation team.

#### HAZ Evaluation Approach

A variety of both quantitative and qualitative methodologies are being used to evaluate HAZs at both the national and local levels. The monitoring and mapping is done through site visits, reviewing all project documentation, meeting with HAZ personnel through organised events and the local/national evaluation network, interviews with key actors, review of performance management reports, baseline statistical data and reports from developmental and learning groups. This process leads to the development of a core data set providing an overview of how all zones are progressing. The different components of the research at the national level is linked through a common approach to evaluation. The approach is drawn mainly from two frameworks for evaluation ; realistic evaluation (Pawson and Tilley, 1997) and the theories of change approach (Connell et al., 1995), already outlined in Chapter 3. Together they provide a theory-based approach to the evaluation of the community health improvement process in HAZ.

This overarching evaluation framework starts with the context within which the HAZ operates; the resources available in the communities and the challenges they face. Next a rationale for intervening in relation to priority issues is specified.

The strategy is then translated into clearly defined change mechanisms, what Judge and Bauld (1999) refer to as purposeful investments in activities, interventions and processes. Targets for each of these investments are specified. These targets need to meet two requirements; 1) they are specified in advance as the expected consequences of actions and 2) these actions and their associated milestones or targets should form part of a logical pathway that leads in the direction of strategic goals or outcomes. Within this approach evaluators work with local stakeholders to promote learning across the entirety of the community health improvement process. A theory-based approach requires that policy makers and practitioners be able to explain their starting assumptions, specify a plausible and preferably evidence-based way; articulate why their chosen investments in interventions and processes will take them in the direction of the long-term outcomes they are seeking to achieve, and identify in advance the expected outcomes/consequences of their actions in ways that lend themselves to being monitored and evaluated (Judge and Bauld, 2001). However, it is interesting to note that this is the area where precisely most difficulties were reported across the HAZ projects.

Judge and Bauld (2001) report some key findings from first wave interviews carried out by the national evaluation team with over 90 key stakeholders in each HAZ in 1999.

They report an impressive range and breadth of project activities across the various HAZ sites. Each HAZ area has selected particular priority issues and as a result different interventions to address these issues. Judge and Bauld (2001) report that one of the most commonly stated goals included the reduction of health inequalities together with building partnerships and promoting community involvement. They also report that questions about strategic approaches being adopted in pursuit of high-level goals did not elicit clear or convincing responses. Considerable uncertainty and resistance was encountered in relation to the emphasis placed on the role and importance of targets in the planning process. Tensions between the pressure to produce short-term targets were perceived as inconsistent with taking community involvement seriously. They report that well-developed strategies linking problems and goals with purposeful interventions and practical milestones or targets were largely conspicuous by their absence.

HAZs are required to produce explicit targets and the evaluation reported quite a lot of confusion about what constitutes an appropriate target. While all the implementation plans were strong on identifying problems, articulating long-term objectives and specifying routinely available indicators for monitoring progress, they were much less able to fill in the gap between problems and goals. The national evaluation team report that only in very rare cases was it possible to identify a clear and logical pathway which links problems, strategies for intervention and milestones or targets with associated time-scales and longer-term outcomes. Frequently targets were highlighted without any accompanying explanation of the mechanisms intended to achieve them.

While there was generally a clear sense of purpose and a marked enthusiasm and commitment to the work of the HAZs there was also growing realisation of the enormity of the task. In many cases, true community involvement was not yet a real experience. Likewise, the rhetoric of partnership was not yet matched by reality in terms of engaging the voluntary sector. Given the deeply entrenched poverty of the communities and the fundamental inequalities in the distribution of power and resources between the different sectors, it was highlighted that the issue of community involvement in partnerships will continue to pose challenges for HAZs.

Sherriff and Webster (2002) give a useful overview of some of the main lessons learnt from HAZs in terms of community involvement work. Most HAZs report that the national level policy context for the work has had a major positive impact on their ability to deliver. They note that policy emphases on tackling social exclusion and inequality through employing community involvement and partnership working have enabled benefits to be more visible and clarified. These include benefits for communities, individuals health organisations and benefits for partnerships as described earlier in Chapter 3. A variety of methods to ensuring community involvement have been used ranging from development of community involvement protocols, to involvement in project steering groups, networking development and participatory appraisal methods.

Among the barriers to community involvement they report:

- concentration on central/national targets, priorities and time scales leading to difficulties in promoting local community agendas.
- uncertainty about future HAZ funding which affects commitment and consequently the quality of engagement
- making sense at local level of separate central initiatives and how they need to be joined up locally
- lack of joint structures for work at local level
- organisational change and restructuring within key partner agencies can distract key individuals
- working across district boundaries can impeded progress
- lack of commitment for an overall joined up community involvement strategy for an area can lead to duplication of staff and community time
- tension about the role of community activists versus democratically elected representatives can halt progress
- lack of middle management understanding and front line involvement in community involvement activities can impeded progress.

To meet the challenges a range of capacity skills and knowledge requirements for staff at all levels are identified, such as expertise in partnership working, building on previous community involvement work, creating capacity to try new approaches, and developing skills in changing processes and cultures not just building structures. Many statutory agencies have been made aware of community involvement and now see it as an integral part of their approach. This has led to greater consultation and community involvement in service planning and delivery. Equally HAZs cite achievements in agencies responding more effectively to needs identified by communities. In particular, they highlight the small grants programmes initiated by HAZs as contributing toward improved access by excluded communities to decision making structures as well as to funds for their own activities.

To date HAZs are providing valuable lessons concerning the opportunities and challenges for community development approaches in addressing health inequalities. There is clearly great potential of learning from these initiatives which will expand when the evaluation has been completed. The evaluation approach adopted, highlights the value of a dual track approach in documenting the findings across the range of HAZ projects both in terms their local processes and overall impacts linked to national policy.

### **Overview**

The evaluation studies reviewed in this chapter highlight the many strengths and weaknesses of community development approaches in tackling health inequalities. They also highlight the complexity of evaluating such initiatives and the difficulties in drawing general conclusions about the relative effectiveness of different approaches. It is clear that the traditionally detached and external role of the evaluator does not meet the needs of the dynamic and multi-faceted community development programmes. Participatory evaluation approaches permit a better understanding of the actualities of programme activities and leads to a better informed assessment of programme processes and outcomes. However, many evaluation studies highlight the need for suitable indicators for assessing project achievements, particularly in relation to intermediate and long-term goals. There is a need to establish whether project objectives have been achieved and through process evaluation the reason for success or failure of projects. Typically, assessing whether project objectives have been achieved give rise to identifying indirect or intermediate indicators of project success. Various indicators have been proposed ranging from the process-oriented assessments documented in this chapter through to more structured approaches such as tools for plotting levels of community participation (Rifkin et al., 1988) and structured scales for mapping and assessing partnerships between agencies (Victorian Health Promotion Foundation) and the perception of community ownership and community competence.

Among the indicators proposed by Barr (1995) to assess empowerment strategies are those that demonstrate evidence of:

- the existence of strong community controlled institutions
- that such institutions have real influence over the public policy agenda
- increased direct control of resources and affairs, including community ownership of community assets, such as premises, equipment and information.
- the performance of power structures are genuinely open to influence
- equity is a demonstrably central principle in the policy process at all levels
- material gains are being achieved for disadvantaged people
- there is strong but accountable representative local leadership
- the performance of professionals reflects the values of empowerment and is evaluated by users
- increased democratisation and decentralisation of services and resources allocation within an overall policy framework designed to promote equity
- that equal opportunity principles are being upheld with evidence corroborated by the view of oppressed minority groups
- personal development of citizens measured not only by increased levels of participation or achievement but also self-esteem.

However, there may be a conflict between the search for indicators informed by positivist or quantitative approaches and the process goals of community health development. Project-specific indicators are needed in community development which take into account the context in which projects are embedded. However, Tones & Tilford (2001) point out that there is a need to acknowledge at the same time that there are processes integral to many projects where knowledge of possible ways of assessing them can be useful if such measures are customised. Hawe (1994) emphasises the importance of having a clear sense of what is being sought and the need to translate project objectives in programme documents into recognisable and meaningful components appropriate to actual programme activities.

This underscores the need for interactive and collaborative evaluation planning between the evaluators and the workers and project members in order to clarify programme objectives and agree the evaluation questions in a collaborative fashion. In this respect it is interesting to note Wallerstein's (1999) experiences concerning the problematic relationship between communities and evaluators and the need to acknowledge the power relationship between a funded evaluation and the programme and the difficulties this may rise to in engaging community members as partners on an equal footing.

In balancing the focus in evaluations between process and outcome indicators, Dixon (1995) advocates the use of a dual track approach which has two complementary elements; a community controlled process evaluation and an externally controlled programme evaluation. As an example of dual track evaluations, she cites the Healthy Cities programme in Australia, which combines locally determined ethnographies for community-led change in the form of a community story approach and a sponsor-backed evaluation making use of co-produced indicators which also reflect community development values. A dual track approach is also employed in the HAZ community projects in the UK where there is both national and local evaluation with planned integration between the two.

Clearly, in evaluating community development projects there is need to demonstrate the link between programme process and outcomes and this requires the use of multiple methods and analytic frameworks that integrate process and outcome data in a meaningful way so that clear statements can be made about how and why programme changes have come about. The HAZ evaluation noted the difficulties encountered by projects in logically linking identified problems, intervention strategies and intermediate and long-term goals. The use of evaluation logic models have proved useful in programme evaluation as they give equal emphasis to process and outcome evaluation and attempt to link the two in a logical and systematic fashion. The sequence of actions influencing intended outcomes are identified and tracked prospectively in order to examine the detail of actual programme delivery.

This form of action-oriented research attempts to relate intended programme outcomes to the realities of programme process and implementation. The practitioner has a key role to play in this process as data on programme implementation are collected as events occur. This detailing of the project or programme in action permits an accurate record of the programme as it unfolds and plays a crucial role in informing the detection of intermediate level changes leading to ultimate programme outcomes.

Ultimately, community health development projects will need to convince the skeptics that a community development approach can create the conditions within which community participation in health in disadvantaged communities becomes genuinely empowering, has a positive impact on health status, impacts on health service delivery by improving access, and leads to a reduction in health inequalities. This will require projects to produce clear and demonstrable project outcomes as well as process indicators and a clear explanation of how and why project results have been achieved. Complex methodological and practice issues will need to be addressed in order to clarify the full potential of community development approaches in reducing health inequalities and to build support for their use among communities, decision-makers and practitioners. Based on the evidence reviewed to date, we conclude this chapter by endorsing the view expressed by Robinson and Elliott (2000); “.. the benefits of community participation, multi-sector partnerships and resources are in and of themselves sufficient ground for the further exploration of community development approaches in health promotion” (p. 231).

## **Chapter 5**

### **Conclusions and Recommendations**

The nature and extent of health inequalities worldwide is now widely acknowledged. The poorest people in the world have the poorest health and die younger in comparison to their wealthier counterparts. Despite international and national programmes such as the WHO Health for All initiative, poverty and social exclusion continue to be key determinants of health inequalities both between countries and within countries. Health inequalities are a feature of most advanced industrial societies. Inequalities are found for illness, disability and conventional indicators of health and by almost every measure of social status. While existing research has concentrated almost exclusively on describing the nature and extent of the problem, there is a relative paucity of research on the most effective policy and practice approaches to reducing health inequalities. In this report we have sought to examine the international literature in relation to the policy, practice and research on community development approaches and their role in reducing health inequalities. We acknowledge that this review may not be fully comprehensive or represent the full range of community health development initiatives, many of which have not been formally evaluated or reported. However, the specific initiatives and case studies reviewed in this report are regarded as illustrative of current international activity and provide a basis on which to assess the potential of community development approaches in reducing health inequalities. We now highlight the key conclusions from the review and point to recommendations for future work and research in this area.

### **Researching Health Inequalities from the Perspectives of those Most Affected**

There is a large body of international research which describes the nature and extent of health inequalities globally. There are many international examples of large scale research programmes that contribute to knowledge about inequalities, such as the cumulative effects of disadvantage over the life course and the use of cohort and panel data to examine the relationship between

poverty dynamics and health with a view to identifying the most significant areas for policy interventions.

However, research on the complex causes of health inequalities and the pathways linking health with broader social determinants is still in its infancy. In recent years, national data sets are becoming available in Ireland, e.g. the national SLÁN survey, ESRI surveys and the Health Research Board funded Unit for Health Status and Health Gain at NUI, Galway. These data sets, together with other national sources, will prove useful in identifying and monitoring national patterns over time in order to inform policy developments in line with international programmes. Given the largely quantitative nature of these data, there is a paucity of more qualitative research which seeks to understand health inequalities from the perspective of those most affected. Research methods, such as the participatory poverty assessment methods used by the World Bank Poverty Reduction Group (Nayaran, 2000), may prove useful in portraying the lived reality of people's lives and in helping to unravel the links between the first hand experiences of poverty and social exclusion and how they impact on health within poor families and communities.

**Recommendation:** Existing and future data sets on health inequalities in Ireland should be effectively disseminated in an accessible format in order to guide policy planning and practice at all levels. Further research employing participatory research approaches is recommended, both to increase understanding of health inequalities from the perspectives of those most affected and to inform strategic action at a grassroots level.

### **Researching Community Level Determinants of Health Inequalities**

The causes of health inequalities are complex. There has been considerable debate in the international literature concerning the relative importance of various explanations. However, most of the evidence strongly points to the cumulative effect of adverse material and social circumstances as the most important determinant of health inequalities. Researchers have pointed to an array of possible mediators in the interface between society and health. These include individual level analysis on the physiological pathways between stress and health, and the role of psychological concepts such as self-efficacy and perceived control. The role of inter-individual level concepts such as social support and social networks have also been explored.

Likewise, sociologists and epidemiologists have documented the links between health and macro-level factors such as social class, ethnicity and gender.

However, there are many gaps in our understanding of community level determinants of health and the links between people, place and health. There is a need to shift the focus from delineating risk groups to identifying risk conditions (Labonté, 1999). In particular, there is need for greater attention to identifying the mechanisms whereby community level factors such as networks and relationships impact on health and how these factors, in turn, are shaped by broader macro-level factors at the community level. As Campbell and Jovchelovitch (2000) point out, an understanding of these processes is critical in determining the mechanisms through which community participation can serve to promote health and reduce inequalities.

***Recommendation:*** Research is needed to identify the pathways by which social structures can affect health status at the community level. There is a need for a greater focus on researching the community level determinants of health in order to establish greater knowledge of the building blocks needed to achieving stronger cohesive healthy communities.

### **Evaluating Policy Impact**

While there are many international examples of large-scale studies on the existence of health inequalities, there is relatively little research which has a direct policy or practice focus. There is a paucity of good evidence on which policies and strategies can best contribute to reducing health inequalities. Bauld & Judge (1999) comment that; “convincing evidence about the likely impact of specific policy initiatives or interventions on reducing health inequalities is highly elusive” (p. 3). While there are a number of international and European networks which seek to exchange knowledge about interventions and policies to reduce health inequalities, few have contributed to the evidence base about the impact that different approaches might have on health inequalities. It remains to be established which approaches are the most effective in reducing health inequalities.

That said, international and national health policies appear to endorse the role of community development approaches and emphasise the appropriateness of community development as a way of tackling the consequences of long-term disadvantage. As illustrated in this report, community health development policy initiatives are being developed to address health inequalities both in Ireland and across the globe. However, there is relative absence of studies evaluating the impact of these policies or indeed evaluating the extent to which policy objectives are actually translated into action on the ground. The influential Acheson report (1998) recommended the use of health inequalities impact assessment in order to determine the impact of social and health policies.

***Recommendation:*** There is a need for policy and practice focused research to inform which anti-poverty measures, social policies and health development strategies might best be advocated for reducing health inequalities. Within the national context, a ‘joined-up’ approach to policy development and implementation across sectors is advocated in order that concerted action may be achieved in reducing health inequalities. Systematic evaluation of the impact of policies is needed in order to determine the extent to which policies are actually implemented on the ground and the relative impact and effectiveness of their implementation. We endorse the recommendation made by Daly and Leonard (2002) that government departments should undertake research to monitor and identify the effects of all policy changes once they are implemented. The development of a health inequalities impact assessment methodology is highlighted in this regard.

### **Building the Knowledge and Capacity to Implement Community Health Development**

Despite a large and growing literature on community development, there appears to be a suggestion in the literature that the use of comprehensive community development approaches is limited and that confusion has resulted from overlapping meanings and the interchangeable use of terminology. Community development has been used an umbrella term to describe a range of approaches.

There is a need distinguish the key differences between the various community approaches being used including: who is involved (one agency, multiple sectors, citizens, community groups), how issues are identified (by the community; by a public health agency) and how programmes are planned and implemented (role of the stakeholders). While the language of community development may be liberally used, translating the rhetoric into practice on the ground depends on a fundamental understanding of what a community development approach entails. Many community health programmes tend to emphasise partnership, participation and collaboration but little citizen control. The key elements of collective ownership, citizen involvement, and community empowerment need to be recognised as central to community development approaches. If we wish to see the use of community development, then by definition it must be community as opposed to agency driven. Only then will we have an opportunity to see community development in action.

***Recommendation:*** Training and skill development is needed in order to produce the high level expertise and resources required and to ensure the development of best practice.

There is a need to refine the understandings of community health development approaches. This is critically important if expertise in the area is to be transferred to practitioners, agencies and community members in order to build local capacity to do community development. Differing concepts and understandings of community involvement will result in different practices and levels of ‘real’ participation. Limited knowledge and capacity for community development is likely a significant limiting factor in the effective promotion and implementation of community health development approaches. Therefore, the development of health practitioners’ knowledge and skills in implementing community development is highlighted as a key area for development.

### **Building on Lessons Learned**

This report has show cased a number of international initiatives which have successfully implemented community development approaches in addressing health inequalities across a range of population groups and health issues.

Chapters 3 and 4 have highlighted the implications for good practice, including the key strengths and weaknesses of community development approaches, and the need to build on lessons learned from existing initiatives.

Community development can be resource intensive and recent recognition of the importance of community development approaches in tackling inequalities is to be welcomed as this provides the policy context within which initiatives can be nurtured. However, critiques of community development approaches also have to borne in mind, in particular concerns about the pursuance of community development unless matched by efforts to address the underlying causes of poverty and disadvantage.

A strong commitment to dissemination has to be built into the work from the outset. This serves an important function both in sharing expertise and informing practice development and also encouraging practitioners to document their experiences of project work and reflect on the key challenges and opportunities encountered. Much of this type of information remains unpublished and is often referred to as the 'wisdom literature' which is passed on informally from one practitioner to another. Opportunities for learning in this developing area must not be missed, and there is a need to build on established expertise. At the national level, the experiences and expertise of community members, workers, practitioners in Irish community health development projects will prove invaluable in informing future developments.

***Recommendation:*** A national forum for dissemination and sharing of practice across different community development initiatives be established with a view to sharing expertise and experiences in project development and implementation. In addition, a qualitative database of current projects and initiatives could be established to promote innovative practice and provide information on developmental work in progress.

### **Evaluation of Community Development Approaches**

While evaluation research to date has contributed to our understanding of the different processes of community development approaches to health promotion, there continues to be little

evaluation of the outcomes of these varied practices. Given the range of approaches used it is difficult to draw general conclusions about the overall effectiveness of community health development approaches in reducing health inequalities. Projects have demonstrated a range of successes both for communities and individuals. The ultimate test will be whether community health development programmes can create the conditions within which community participation in health in disadvantaged communities becomes genuinely empowering, has a positive impact on health status, impacts on improved access to health service delivery and leads to a reduction in health inequalities. There is a need to identify what baseline indicators should be used or developed to describe variations in the health and well-being of local community populations. The prospective tracking of such indicators is also needed in order to monitor the extent of change over time and the degree to which observed changes may be attributed to the project.

***Recommendation:*** The relative effectiveness of the variety of community approaches and diverse implementation methods used need to be evaluated. Project evaluation needs to be undertaken in terms of both process and outcomes and critically, there is an urgent need to establish more clearly the nature of the relationship between the two. In methodological terms there is a need to examine the use of suitable baseline measures together with appropriate indicators of intermediate outcomes which may be used as precursors to health status and health systems change. There is also a need to establish the cost-effectiveness of community development approaches, both in terms of the deployment of human and financial resources and the broader added-value of such initiatives beyond the health area.

### **Developing Appropriate Evaluation Skills**

The evaluation approaches used have varied and while strong preferences for process approaches are often found, there is plentiful evidence for the pragmatic adoption of methodological pluralism and dual track approaches. Resources are limited and these need to be used wisely.

Multiple research methods are required to address many of these key research questions as there is a need to capture project process and outcomes at different levels. The formulation of logic models provide a very useful opportunity for evaluators and practitioners to share their perspectives and expertise in formulating project design, sequential planning and the clear

identification of project goals, desired outcomes and the project activities necessary to achieve them. Logic models also provide a useful blueprint for sharing perspectives in monitoring the process of programme implementation and collaboration. International studies have highlighted the need to provide technical support and assistance to project workers and practitioners in engaging in these evaluation activities.

***Recommendation:*** There is a need to build the capacity and confidence among project workers and evaluators concerning the use of collaborative and participatory models of evaluation. Evaluation planning needs to be built into community development projects from the outset, as this plays a key role in clarifying key project objectives, processes, and intermediate and long-term goals. The necessary skills and capacities to undertake this work cannot be taken for granted and collaborative evaluation skills will need to be developed and supported.

### **Bridging the Gap between Theory, Research, Policy and Practice**

There is a long history of work on community development projects, which has been accompanied by the development of theory and research from Freire's (1973) work through to the present day. The key principles underpinning community development interventions revolve around the idea of empowering communities to participate, both in the construction of the relationships that form the community itself, and also in the broader social arenas. As Campbell and Jovchelovitch (2000) point out, participation and community action are the key mechanisms through which deprived sectors can reclaim their interests in the public sphere, reaffirm their identity in relation to their social groups and pressurise channels of decision making and institutional power to respond to their needs. The level of community participation is central to thinking about health in conditions of poverty and exclusion.

Therefore, the concepts of participation and empowerment are key to reflecting and theorising about community health development. Keeping alive the vital link between theory, research practice and policy is key challenge in developing the knowledge and practice base in this area. There is a need to demystify and democratise the knowledge development process and to recognise how much can be learned from concrete and practical interventions, where theories are put to use. Policy makers, academics and health professionals may be quite comfortable adopting the language of community health development but perhaps less so with the realities of what

translating these principles into practice actually means. In contrast, community members participating in community development work may not be comfortable with the policy and research jargon but do have first hand knowledge and experience of the empowerment process, although this knowledge may remain at an implicit level rather than being explicitly formulated.

Oakley and Oliver (2001) call for a jettisoning of the old polarities of research and practice, professional and lay, individual and the system and highlight the need for the integration of these perspectives. The meeting and sharing of these perspectives is where paradigm shifts can occur in terms of understanding and bringing about change. This is particularly important in the health area, if we are to bring about a shift from the more traditional bio-medical model to a truly social model of health, where the root causes of poverty, social exclusion and their negative impacts on health and well-being are fully understood.

***Recommendation:*** As a first step in promoting greater links between the principles, policy and practice of community health development, policy makers, academics and professionals who have an influence in the area, should be required to visit community development projects, to meet with the people involved and witness the policies and theories in action. At a more strategic level, a national community health development network could be established in order to take forward the development of community health development in a co-ordinated and integrated fashion and to consolidate the link between theory, practice and policy. The proposed grouping could include key players in the areas of policy, research and practice. Such a network could liaise with key players in Northern Ireland, the UK, and the wider European and international arena to promote shared learning and to stimulate joint research and development activities on a strategic basis. Given the complexity of tackling health inequalities, community health development requires new ways of thinking and innovative approaches. Bringing together the key players across the various sectors could be an important tool for improved and shared understanding in the field.

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[Http://www.who.int//](http://www.who.int//)

# Appendices

**APPENDIX 1:**

**Questionnaire on Community Development  
Health Initiatives**

Centre for Health Promotion Studies,  
12 Distillery Road,  
Newcastle,  
Galway  
25<sup>th</sup> November 2002

To Whom It May Concern:

I am currently carrying out research on Community Development Approaches to Health Inequalities on behalf of the Combat Poverty Agency (Ireland). This research involves an international literature and policy review examining the role of community development approaches in tackling health inequalities. I therefore, wish to document existing projects that are ongoing in this area. In particular, I am interested in identifying case studies of selected community health development initiatives in order to highlight examples of good practice.

With this in mind, I would be most grateful if you could fill out the attached questionnaire and return to me in the stamped addressed envelope by the **9<sup>th</sup> of December 2002**. Also, I would very much appreciate if you could forward on any relevant information relating to your project such as publications, annual reports, evaluations etc. Details of other related projects in this area are also welcome.

I look forward to hearing from you.

With best regards,  
Yours Sincerely

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Pamela Mahony  
Project Researcher  
+353 91 524411 ext: 3465  
Pamela.Mahony@nuigalway.ie

# Community Development Approaches To Tackling Health Inequalities

This questionnaire aims to collect information on community-based projects and interventions that are intended to tackle health inequalities.

**What is the title of the project?** \_\_\_\_\_

**Name of contact person in the organisation?** \_\_\_\_\_

**Email Address:** \_\_\_\_\_

**Telephone Number:** \_\_\_\_\_

**When was the project established?** \_\_\_\_\_

**How was the need for the project identified?** (*Needs analysis, consultation with the public?*)

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**What are the aims and objectives of the project?** \_\_\_\_\_

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**Who are the main groups targeted by the project?** \_\_\_\_\_

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**How is the project funded? (Please list funding agencies)** \_\_\_\_\_

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**To date, what have been the outcomes or achievements of the project?** \_\_\_\_\_

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**What is the level of participation in the project, i.e. number of participants?** \_\_\_\_\_

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**What is the period of implementation of the project e.g. January 2000 – December 2003?**

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**If the project has been completed, has a report been written? \_\_\_\_\_**

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**Was a formal evaluation conducted? \_\_\_\_\_**

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**If so, is the report available? \_\_\_\_\_**

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**Has the project contributed to tackling health inequalities? \_\_\_\_\_**

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**Are there any other observations, thoughts or feelings about the project itself that you would like to add? \_\_\_\_\_**

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**Thank You, Please Return Questionnaires by the 9<sup>th</sup> of December 2002 to:**

Pamela Mahony,

Centre for Health Promotion Studies,

12 Distillery Road,

National University of Ireland, Galway

Phone: 00 353 (0) 91 524411 extension 3465

**APPENDIX 2:**

**HAZ Evaluation Questions**

**Key Research Questions (Taken from HAZ. (1999) *Learning to Make a Difference*.  
Department of Health: London)**

In order to understand not only *whether* HAZ objectives are achieved, but also *how* they are achieved or *why* they are not, it is necessary to pose a series of evaluation questions. These should reflect the various contexts within which the initiatives are operating and the assumptions or hypotheses underpinning the national and local change strategies proposed. Based on our collective experience to date, we have identified a number of key research questions. We suggest that these should provide a framework within which the next stage of the national evaluation should be conducted. The questions are not meant to be exhaustive. However, they are intended to cover what we perceive to be the issues of central importance in relation to:

- the national policy context within which HAZs are expected to operate;
- the opportunities and obligations made available to them in the form of means
- the local contextual framework within which partnerships and learning organisations can be developed;
- the intermediate objectives of modernising services, promoting community involvement and tackling the root causes of ill health; and,
- the primary outcomes of interest to citizens and policymakers - better population health and wellbeing especially for the worst off.

**National policy context**

- How consistent, clear and feasible are policy messages, guidance and advice from the DH/NHSE to health action zones? In particular, are policy messages in respect of HAZs consistent with the overall direction of health policy?
- How well integrated with other central government initiatives (such as SRB, New Deal for Communities, Education Action Zones, Sure Start etc.) is HAZ policy
- To what extent have central-local relations changed in ways that encourage or inhibit innovation and risk-taking at the local level?
- Is there any evidence that national policy learning benefits from local experience with HAZs?

### **The Means: opportunities and obligations**

- Has an appropriate balance been struck by the DH/NHSE in offering finance, flexibility and freedoms to HAZs in return for quite tight performance management of detailed implementation plans?
- What mix and level of freedoms, flexibilities and resources are necessary to support and sustain local partnership working?
- What level and type of performance management is required to satisfy national and local stakeholders that HAZ objectives are being pursued?
- In what circumstances do specific freedoms and flexibilities make the most effective contribution to achieving HAZ objectives?
- To what extent has new finance facilitated positive changes in terms of leveraging extra resources, removing blockages to innovation or reshaping mainstream services?

### **The Local Framework**

- Which baseline characteristics of the local environment – such as economic and social conditions, political culture, history of interagency working - have greatest significance in terms of helping or hindering HAZ development?
- What are the most distinctive aspects of partnership working that best facilitate local policy, strategy and practice development?
- What are the most effective ways of ensuring that HAZ partnerships are integrated within other wider local partnership processes?
- What are the relative costs and benefits of partnership working?
- To what extent do all the ‘partners’ within the HAZ feel able to influence the development and implementation of HAZ strategy?

### **Learning organization**

- In what ways do different styles of learning within and between organisations contribute to the community health improvement process?
- What different approaches are adopted by HAZs to the management, monitoring and evaluation of interventions, activities and processes?

- What different approaches are adopted by HAZs to promote policy and practice learning by local stakeholders?
- To what extent can different styles of learning organisation across the HAZ community be identified?

### **Intermediate Outcomes, Strategies and Domains**

- What variations can be observed in the general strategic direction of HAZ programmes?
- To what extent and how are local stakeholders able to articulate a clear rationale for the strategies adopted by HAZs and to specify the expected consequences of the investments they make?
- What evidence is there that different strategies are capable of sustaining momentum and building the capacity for enduring change?

### **Reshaping the health and social care system**

- What similarities and differences in approach to the modernisation of the health and social care system are being adopted by HAZs?
- To what extent have HAZs promoted the development of closer relationships between health and social care agencies in ways that yield better services for users?
- In what ways are health and social care interventions seen as an effective means of achieving desired changes in population health and well being?

### **Promoting Community Involvement**

- What strategies are being developed by HAZs to promote community involvement to achieve increased accountability, improved health, more sensitive services, more cohesive communities and to enhance reciprocal learning?
- What is the impact of community involvement on the achievement of process objectives and substantive goals?
- Can HAZs create the conditions within which community involvement becomes genuinely empowering?

### **Tackling the root causes of ill health**

- What similarities and differences in approach are being adopted by HAZs to tackle the root causes of ill health?
- In what ways and over what period of time do key stakeholders expect HAZ activities to achieve desired improvements in population health outcomes?
- In what ways do HAZs try to place health issues on to the policy agendas of other agencies?
- What level of success do HAZs achieve in influencing changes in health-related policies and practices that lie outside the traditional health and social care system?

### **Population health and well-being**

- What baseline indicators can be identified or developed to describe variations in the health and well being of local HAZ populations?
- To what extent can changes be observed in these indicators during the lifetime of the HAZs?
- To what extent can changes in outcomes of primary interest to stakeholders be attributed to specific aspects of HAZs?
- What is the impact of each of the key building blocks of HAZs (as illustrated in the conceptual framework we have adopted) on key goals and outcomes?
- What are the implications for future policy and practice development of a comparative analysis of context-mechanism-outcome configurations across HAZs?
- What contribution has the HAZ initiative made to the national policy goals of modernising health and social services and reducing health inequalities?
- analysis of context-mechanism-outcome configurations across HAZs?
- What contribution has the HAZ initiative made to the national policy goals of modernising health and social services and reducing health inequalities?

**APPENDIX 3:**

**Primary Health Care Modules in the Galway Travellers  
Support Group**

Table 2: The Progression of Modules over Three Years

Year One Sept 2000 - July 2001	Year Two Sept 2001 - July 2002	Year Three Sept 2002 - July 2003
Introduction to Personal Group Development and Communication	Principles of Communication.	Advanced Communication and Personal Group Development  Theory to Practice
Introduction to Community Development  Introduction to Research Methods  Consultation	Principles of Community Development  Principles & Practices of Research Methods and Techniques  Active Participation	Community Theory and Practice  Practical Research Skills
Introduction to Primary Health Care  Introduction to Health Services  Basic Health	Principles & Practices  Alternative Models  Why Prevention Programmes  Concepts of Health, Physical, Emotional and Spiritual.	Practicality & Approaches  Involvement with Health Services  Putting over the Message  Community Health
Introduction to Traveller Issues.  Discrimination and Equality  The Task Force	Understanding of Traveller Issues in Society.  Further understanding of Equality  Tackling Discrimination  Identity and Culture  Social Inclusion	Assessment of Traveller Issues  Ideology  The Traveller Voice  Sexism
Introduction to Literacy and Numeracy  Introduction to Computers	Further Development of Literacy and Numeracy according to Individuals Needs & Goals  Further Training in Computing	Understanding of Literacy and Numeracy  Practical Computing

