

**Community Development and Primary Care  
in Northern Ireland and England**

**Dr Philip Crowley**

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**Combat Poverty Agency  
Bridgewater Centre  
Conyngham Road  
Islandbridge  
Dublin 8**

**Tel: 01 670 6746  
Email: [info@combatpoverty.ie](mailto:info@combatpoverty.ie)  
[www.combatpoverty.ie](http://www.combatpoverty.ie)**

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## **Community development and Primary Health Care in Northern Ireland and England**

**Dr Philip Crowley, for the Combat Poverty Agency**

*This paper is dedicated to the memory of Dr Fiona Bradley a general practitioner whose commitment to equality inspired many.*

The Combat Poverty Agency has a role in promoting and supporting community development as a means of tackling poverty and social exclusion. It also has a commitment to promoting the participation of excluded groups in the development of more effective public policy and practice.

As part of its work on poverty, health and community development, Combat Poverty commissioned this short piece of work to review links between community development and primary care/general practice, and to draw on experience and examples in Northern Ireland and England.

It is intended that this paper will identify and analyse

- the experience of participation of people who experience poverty, and those who represent them, in strategies and initiatives in primary care in Northern Ireland and England
- how community development responses to health have engaged with and influenced the development of strategies and initiatives
- the extent to which health care practitioners have embraced community development approaches within their own work methods / practice.

The rich experience of community development and health work in Ireland has been drawn together in another document commissioned by Combat Poverty, and undertaken by the Community Development and Health Network, Northern Ireland. Despite the many examples of community development approaches in health identified, there were few examples of community development specifically linked to and influencing primary care. This is probably as a result of the fact that general practice services are only beginning to consider the importance of linking into local communities.

A golden opportunity currently exists in Ireland to advance community participation linked to general practice and primary care, based on community development principles. The policy commitment to community participation in the Primary Care Strategy and the funding for the development of ten demonstration Primary Care Teams, suggests that there has never been a better time to develop community participation, building on the extensive experience of community participation in other arenas of social partnership.

The paper is intended to contribute to the discussions and debates developing around the implementation of the Health Strategy *Quality and Fairness* (Department of Health and Children, 2001) and the Primary Care Strategy *A New Direction* (Department of Health and Children, 2001). It will also identify models of practice that might be built upon in the Combat Poverty Agency's *Building Healthy Communities* Programme.

The Framework Document for the revised National Anti-Poverty Strategy (NAPS), 2001, P.34, suggests that:

*'Health care services should be centred on people's needs. This requires consultation and a community development approach involving people and communities in assessing their own health needs and in various stages of design, delivery, monitoring and evaluation of health and personal social services. This issue is particularly relevant to primary care services'.*

This paper sets out

- An understanding of community development and health
- Examples of community development and primary care in Northern Ireland and England
- Ingredients of good practice
- Republic of Ireland context
- Conclusions
- Appendix 1 lists the current ten demonstration Primary Care Teams
- Appendix 2 outlines different possible methods and levels of public involvement in health

## **1. Community development**

A scoping document on community development and health in Ireland, undertaken for the Combat Poverty Agency by the Community Development and Health Network, Northern Ireland, highlighted many initiatives that were described as community development but lacked core elements of community development. Many were, in reality, community-based activities or service delivery initiatives. This is an important distinction and underlines the importance of being clear about what we mean when we refer to community development.

### **Definition of community development**

Community work/development, as defined by the Community Workers Co-operative:

- Involves and enables people to work together to exert control over issues that affect their lives;
- Has a collective focus rather than being a response to individual crisis;
- Challenges inequitable power relationships;
- Promotes redistribution of wealth and resources in a more just and equitable fashion;
- Is based on participative processes and structures;
- Is based on solidarity with the interests of those experiencing social exclusion;
- Presents alternative ways of working;
- Seeks to build alliances with other organisations challenging marginalisation in their own countries and globally.

The following definition was developed by community development workers in the field, based on the UK Federation of Community Work Training Group's work and endorsed by the UK Standing Conference on Community Development (SCCD):

- it is concerned with issues of powerlessness and disadvantage and is based on sharing power, skills, knowledge and experience
- it seeks to enable people to grow and change according to their own needs, providing they do not oppress others or damage the environment

- it aims to empower and enable those traditionally deprived of power and nurtures collective action on the community's agenda and it encourages genuine participation
- it challenges individuals, policies and practices that discriminate unfairly against black people, women, people with disabilities, lesbians and gay men, older people and others disadvantaged by society (SCCD, 1992)

### **Definition of Community Development and Health:**

Webster (1990) has described community development and health as:

*'helping those involved to look at why their health is the way it is' and 'helping groups take action over their own health...and feed into an ever more effective health policy'*

Thus it is not just about community organisation but also about institutional change.

The Community Development and Health Network, Northern Ireland, has defined community development and health as follows:

*'A community development approach to tackling health issues involves local people such as themselves, coming together on their own or with others interested in health, to work out what the problems are, getting organised and taking action on health issues of concern to them.'*

### **Characteristics of community development which could contribute to tackling inequalities in health**

- it is the most likely approach to ensure the involvement of people who live in disadvantaged communities and minority groups
- it creates opportunities for dialogue in order to democratise decision-making which requires investment in those members of the community who are actively participating
- it identifies and sets out the community's agenda and it grows and flourishes when communities see changes to which they have contributed
- it uses existing networks, creates new alliances and uses innovative methods to encourage participation through ensuring accessibility
- it ensures that service provision is more relevant and effective

**Community development can contribute to a 'real' engagement between general practice and communities provided that:**

- the structures set up within Primary Care provide accessible channels of communication
- community development work is funded and supported
- people's contributions are valued and taken seriously
- existing community development projects are supported and sustained so that immediate opportunities exist to build upon their history, local knowledge and networks
- proposals for service development are not confined to traditional definitions of health but respond to the 'community's' view of health i.e. a holistic approach encompassing crime, fuel, benefits, jobs, transport etc. (Crowley et al, 1998)
- the definition of 'community' applied encompasses the full diversity of Irish communities and can be defined as communities of identity and interest

A community development approach to developing community participation in primary health care in rural Ireland has been described in the past (Quirke et al 1994) and been shown to be effective. Pavee Point has developed a successful participatory primary care model, in which Travellers have developed and delivered a programme of primary health care, based on the expressed needs of the community.

## **2. Community development and Primary Care in Northern Ireland and England**

### **2.1 Community development and Primary Care in Northern Ireland**

#### ***Policy background***

The policy commitment to community development is much clearer in Northern Ireland than in England and the Republic of Ireland. The DHSS document *'Mainstreaming community development'* acknowledged, however, that it was still at an early stage of development in 1999, and highlighted that Boards and Trusts did not have a policy for community development (DHSS, 1999). A recent survey highlighted that over 50% of community development and health projects in Northern Ireland are reliant on time-limited EU Peace and Reconciliation funding and few are funded by the Health and Personal Social Services (Ginnety 2000).

*Investing for Health*, the 2002 Public Health Strategy for Northern Ireland, commits to encouraging community involvement in improving health (Department of Health Social Services and Public Safety, 2002, p18), gives support to a community development approach and proposes organisational and technical support to ensure community capacity to participate (Department of Health Social Services and Public Safety, 2002, p128). In describing Local Health and Social Care Groups, they are seen as enabling primary care professionals to look at the broader needs of local communities in promoting the health and well-being of the local population.

The Department of Health, Social Services and Public Safety consultation paper on the future of Primary Care commits to a *strong input for local communities and service users* (Department of Health and Social Services, 200, p6). The Health and Social Care Groups (like the Primary Care Groups and then Trusts in England) are the first time that Primary Care Teams have organised collectively across wider and coherent geographical areas. This clearly offers a new opportunity for community development work to develop links with Primary Care. In reality these groups have failed to engage the GPs due to reservations

from the British Medical Authority and their community representatives have been appointed formally, following advertisements in the press (Livingstone 2002). This approach to selecting community representatives is likely to exclude most representatives from marginalised communities and minority groups.

Equality legislation and efforts to promote social inclusion are potential levers to support community development in that community development prioritises tackling inequalities experienced by disadvantaged communities, including minority communities of identity and interest. All health boards now have community development strategies, but adopt different approaches. Some of the Health and Social Care Trusts have employed community workers and teams and in Craigavon and Banbridge, for example, the team has provided support, expertise and funds for local community groups and helped the formation of networks (Craigavon and Banbridge 1999).

There is a strong and extensive Community Development and Health Network in Northern Ireland, unlike in England. It has been contracted to deliver community development training to the new Health and Social Care Groups. It has also supported some community activists in the formal appointment process to become lay members of these groups. It will be supporting these lay representatives to work together and to link to local community networks and to become accountable in this way. In this way, some of the limitations of the selection method for community representatives may be overcome.

## **Some models of Community development and Primary Care from Northern Ireland**

### ***Garran and Croob Cross Community Association***

This originated in a primary care needs assessment based on a rural general practice, and led to the appointment of a development worker. This is unusual in that most community development attached to Primary Health Care has developed in urban areas. The added challenge in rural areas is to get people together over wider geographical areas. The GP practice importantly covers most of the local area. In a sectarian context with a potentially divided community, the GP surgery was seen as

'neutral territory' and health as an issue on which to come together. The work commenced with a Participatory Rapid Appraisal of health needs which went on to maintain community engagement by the appointment of a community worker and action on expressed needs (O'Brien et al 1999). Participatory Rapid Appraisal is an approach that involves engaging key local stakeholders in a process of defining the issues that need to be addressed in a local community.

### ***Kilrea General Practice***

A General Practice surgery where the practice manager worked to involve the community, specifically by building an extension to the surgery which is used as a community facility.

### ***White Rock, Belfast***

The community association has worked alongside the practice and employs community workers and peer educators working on drugs education and sex education for young people.

### ***Creggan, Derry***

There is a large community initiative which works closely with the local primary care team and has thus accessed Healthy Living Centre lottery funding. The lottery bid has been driven by the local community but discussions with local general practitioners have led to the possibility of the practice coming in as a partner in the future operation of the centre if the bid is successful. This will have the added advantage of bringing primary care services into an area where there are none presently.

## **2.2 Community development and Primary Care in England**

### ***Policy background***

Despite the commitment to working with the community and the public, the true emphasis in the National Health Service (NHS) remains on the involvement of patients and patient groups in decisions affecting their individual care or specific health service area. There have been a number of notable exceptions, but initiatives to involve local communities remain limited. Community development and primary care has been the subject of

publications for a decade or more (Heritage 1994, Gilbert 1995, CanagaRetna 1997, Fisher et al 1999, Smithies and Webster 1998, Draper and Hawdon 1998). There has also been a long history of community development projects focussing on health, but without health service funding or connections (Smithies 1996).

Many recent policy initiatives have highlighted the need for greater public accountability and participation for communities in decision-making in health, such as: the NHS plan (Department of Health 2000), Saving Lives - White Paper on Public Health (Department of Health 1998), and Health Action Zones.

Within the NHS, there are clearly tensions between the consumerist model of involving patients in designing NHS care and working with citizens and communities to improve health and influence health care. The NHS plan, and the more recent *Involving Patients and the Public in Healthcare* discussion document (Department of Health 2001), commit the NHS to a more consumerist model than promoted previously. The plan talks of patient fora (not dissimilar to proposed 'consumer panels' in the Irish Primary Care Strategy) and patient advocacy and liaison services, rather than committing to community development and democratising decision-making.

Primary Care Groups (PCGs) and subsequently Primary Care Trusts (PCT) represent the first organisational arrangement where GP practices and staff have worked together to develop services in geographical areas rather than simply deliver individual services to their own patients. These PCTs are often co-terminous with local authorities and the possibility for partnership working on the determinants of health is obvious. This coincides with a period where local authorities' roles in health have been promoted by the NHS plan, which defined a key role for local Authorities in the scrutiny of local health services.

At national level a Commission for Patient and Public Involvement was established in January 2003. Its remit is to support patients and the public to have their say, and to work with traditionally marginalised groups to ensure their involvement (National Primary Care Development 2003). This will be difficult if it is organised from a national level. The Transition Advisory Board on Patient and Public Involvement suggested in their final report, before the establishment of the Commission, that they will seek Community

Health Council (CHC) members to fill places in the new PCT patient Fora (Transition Advisory Board 2002). The Community Health Councils were abolished because they were unrepresentative, so this appears like a move back towards the status quo. It appears from this report that responsibility for engaging with community networks will lie with the national commission staff, which seems potentially unworkable. The NHS Alliance (the organisation that represents Primary Care Groups and now Trusts across England), in its position paper on public involvement, proposes that the Fora need to be careful in recruitment. They need to avoid excluding marginalized groups and to use community development to create links with communities of geography and of interest (NHS Alliance 2002). They warn that the agenda of the Fora must be set by local people.

Some feel that the future of community development initiatives linked to Primary Care is fragile in the face of the new focus on 'patient' fora (Drinkwater 2003). They are concerned that the focus may be on improving service quality rather than improving health which may lead to a more adversarial interaction with Primary Care (Drinkwater 2003). One study suggested that over 60% of PCTs are funding community development activity (Gillam and Florin 2002). On the other hand, a survey of Primary Care Groups (this was carried out before PCGs evolved into PCTs) found that public involvement came 9<sup>th</sup> out of a list of 13 key concerns for chief officers (Anderson and Florin 2000).

The reality of much of the existing initiatives to engage local communities in health is that progress has been extremely patchy and it has not had the priority it needs to enter the mainstream (Coote 1993, Freeman et al 1997, Smithies and Webster 1998). Clearly the requirement to develop patient fora may undermine those primary care organisations that have invested in community development.

In Scotland a literature review on public involvement in health found few **written** accounts of community development linking to statutory health care or general practice (Ridley and Jones 2002). This is in spite of the fact that there is known to be an extensive practice base.

## **Some models from England**

### ***Community Action on Health, Newcastle Upon Tyne 1994-2003 – a short case study***

After a consultation with the local community in 1994, the Health Authority and a general practice Locality Group (an attempt by general practices to work collectively that pre-dated but influenced the development of Primary Care Groups - PCGs), funded a community development work post that was accountable not to them but to the local community. The worker visited more than 90 local community groups and worked with them to develop their health agenda and proposals for improvements in existing services. The focus was on networking groups to explore common issues and to negotiate with the relevant health services and local authority management to push for the changes the community had identified as a priority (Crowley et al, 2002).

The work actively sought to involve groups who are often particularly marginalised such as the Black and Ethnic Minority communities, low income groups, lesbian and gay groups, older people, adolescents and people with a physical and sensory disability. Resources were secured to allow for the provision of crèches, carer support, sign language interpreters and ethnic language interpreters. The work has been dependant on a vibrant network of community development projects in the area (Freake, Crowley et al 1997).

An annual health conference is held, with over 200 attending where the year's proposals are prioritised by local people. The worker was funded by the Primary Care Group and then Trust. The community nominated a group of local people called 'Community Action on Health' to follow up the issues raised with action and to give direction to the work of the development worker - this is the prime method for accountability of the worker to the local community.

Instead of advertising for a "lay representative" the PCG agreed that two representatives be elected through the Community Action on Health network and that they develop a form of community representation more accountable to the local community. There was a network of ongoing, supported, community involvement initiatives at the three local PCG areas across Newcastle. Three

people from local community networks are now non-executive board members of the new Primary Care Trust (PCT).

Recent independent evaluations of the work highlighted the fact that a community development approach has been useful in engaging with a large number of local community groups and representatives and has created a systematic focus for the PCG on health inequalities and discrimination against minority groups. Representatives from different communities felt that it had helped them better understand the issues of discrimination against minority communities in that it was the first time some of them had worked with disabled groups or Black groups. (Green 1999)

### ***The Wells Park general practice and community development project, London***

The Wells Park Health Project was set up in 1984 with funding from the Greater London Council. Its aims were to promote user involvement and community development in primary care in Lewisham. It was based in the Wells Park practice initially and had both community development workers and a research worker.

It rapidly established a number of groups in response to local need, as identified both by outreach work and by formal questionnaire. In the next phase of development, the project began a series of Needs Assessments from users' points of view; African-Caribbean (led to the appointment of a community development worker for the needs of this community); Young People's (led to the appointment of a Youth Health Advisor); Housebound Elderly; and users of local mental health services.

It is now transformed into the Lewisham Community Development Partnership, funded by the PCT and still run by a Management Committee of local residents. The organisation is now Lewisham-wide and has different priorities including: supporting practices in involving users, the public and carers; ensuring a community development presence in each neighbourhood and a support network for young parents.

### ***East Wakefield Primary Care Trust***

This PCT is renowned for its work in community development. It currently employs seven community development workers funded from urban regeneration funding and the Health Action Zone. They have done targeted work to ensure the involvement of

communities of interest and identity. The Director of Public Health is non-medical and has championed this work – showing the importance of having some key allies. Much of the areas of work were started with participatory needs assessments. Various community initiatives have resulted from this including a 'Healthy Living Centre' and community health projects. Most significantly, the funding for the community development work has recently been ensured from the mainstream PCT budget. Primary care staff are undergoing training in community development principles and practice. Their work programme now reflects a broad vision of health and a commitment to tackle some of the determinants of ill health identified by the community.

### ***Community development and Primary Care in Bradford***

Work with the community on health issues was started by the Health Action Zone in Bradford. The community involvement team worked with geographical communities and communities of interest and identity. It has focused on building community involvement in PCTs. The team is made up of a manager and one team member in each of the four PCT areas. All PCTs now have public involvement strategies and they have been drawn into local regeneration initiatives. A recent evaluation (reference Bradford) suggested that the PCTs are not yet being influenced by the community agenda but are trying to listen. This illustrates the important point that it is no good developing great work with the community if the health organisations are still closed to outside influence. Work on both needs to go hand in hand. As the evaluation put it: *organisational development is an important building block for community involvement* (South 2002). PCTs in Bradford are funding initiatives tackling the social determinants of health. There is an inter-agency Health Equality Action Team seeking to tackle inequalities experienced by minority groups.

### ***The Vauxhall Health Forum***

This forum of local residents in Liverpool was formed after public meetings to discuss health issues. The Health Authority, after discussions with the forum, funded two GPs to spend a year clarifying health needs. The proposals to plan future services in partnership with the local community, to open a community café and appoint a lay health worker were being pursued subsequently by the GPs.

### ***Heeley Health Project***

This arose out of discussions between local community workers and the members of the local primary health care team in Sheffield. The result was a successful bid for funding to establish an independent community health project and the practice staff contribute to many joint ventures between the project and the practice. The project works with many local people who are not patients in the practice.

***Further examples of approaches to community involvement within primary care are summarised in the following five initiatives:***

#### ***1. Patients as Teachers***

Lewisham in South-East London have developed this approach in which groups of users determine collectively what they feel is good general practice and then teach the subsequent recommendations to the primary care professionals.

#### ***2. Critical Friends Groups***

North and East Devon Health Authority have developed Critical Friends groups attached to general practices. 50 people per practitioner are involved in identifying service improvements at a very local level.

#### ***3. Central Croydon PCG***

This PCG used the existing Croydon Voluntary Action and their health workers to develop a community forum. This was a source of accountability for the lay representative on the PCG board but the agenda was driven by the PCG.

#### ***4. Hackney PCG***

Officers from this PCG went out to meet local community groups on their own territory, an important approach, and they formed a community participation sub-group. It struggled to act on the issues raised by the community however.

#### ***5. Dagenham PCG***

This PCG also had a patient participation sub-group who carried out a significant piece of qualitative research on the needs of those highly dependant on services.

### **3. Ingredients of good practice in community development responses to primary care, arising from these examples**

- Community development linked to primary care is most effective when general practices work together and cover coherent geographical areas.
- Key allies in primary care, such as managers with a commitment to working with communities, are important to get community development started.
- Community development can be undertaken linked to an individual practice, but it must be free to work with all the local community and not just the practice population.
- The practice(s) can support by providing a home for community activity, ensuring funding, resourcing local groups with information, and by creating partnerships with other local agencies to achieve the changes identified by local communities.
- An individual within the primary care organisation needs to be identified to lead on the development of community involvement.
- Communities should be engaged within their own community centres or meeting places.
- Links should be made locally with grass-roots organisations working with local people/communities and their financial stability should be a priority for statutory agencies.
- Building development in local communities should be done in partnership with the other statutory, voluntary and other agencies.
- Those who are to develop public participation need to get commitment from the top of their organisation for the role of the public/community in their decision-making. Resources need to be identified to guarantee the work.
- Community representatives need support to be accountable to the wider community and community development input should be accountable to the local community and not the health organisations.
- Any approach must involve those experiencing disadvantage, social exclusion and marginalised minority groups - people with sensory or physical disability, lesbians and gay men, and ethnic minority communities. Community development is particularly suited to this task.

- Financial support is necessary to ensure access - crèche, carer support, interpretation (incl. British Sign Language) translation and audio-tapes etc.
- To involve the public, health and local government decision-making bodies need to be developed so as to be responsive to the community's view.
- Community involvement should contribute to tackling health inequalities and poverty by ensuring those who experience poorer health or poorer access to health services are involved and that the agenda tackled has equality as a main priority.

There are a few examples of where the impact of the community development work linked to primary care/general practice has been identified. The impact is not easy to assess. Some have demonstrated the effectiveness of community development in engaging significant numbers of local people, especially including hard-to-reach groups. They have also shown the extent to which community development approaches have maintained a policy focus on health inequalities. Some evaluations have highlighted the initiatives that have resulted from this work, aimed at meeting the expressed needs of local communities. A review of studies on involving the public and patients in health care shows a lack of research on the effects on quality and effectiveness (Crawford, 2002).

There are a number of guides to developing public involvement for Primary Care (Scottish Office 1999, NHS 1998, Anderson 2000, NHSE 1997, Freeman et al 1997, Community Development and Health Network 2000, Ginnety 2001)

#### **4. Republic of Ireland Context**

Significant challenges face those concerned with the public's health, including 1) the profound level of inequality existing between people from different socio-economic groups 2) the added discrimination and poor health suffered by many minority community groups of interest and identity, such as ethnic minorities, and people with a disability, and 3) the health issues facing both women and men. The all-cause mortality rate, on the island of Ireland, in the lowest occupational class is 100-200% higher than in the highest occupational group (Balanda and Wilde 2001).

Inequalities in health are often compounded by inequalities in access to health care. In Dublin, for example, there is evidence that general practices are heavily concentrated in more wealthy areas (Sinclair, Bradley et al 1997). There is also some evidence from England that patients from lower socio-economic groups, and ethnic minority groups, are less likely to get referred from general practice to hospital care (Ahmad, 1993). People with disabilities have significantly worse socio-economic status and suffer many obstacles in accessing health services and lesbians and gay men report the unwelcoming nature of most health care settings (Court and Cheetham 1999).

The Irish health services face major challenges if they are to truly embrace an equality agenda. The Equal Status Act 2000 underlines the importance of an equitable service provided irrespective of gender, ethnic minority status, disability, age, sexual orientation, family status, marital status and religion and membership of the Travelling community. It has also been recommended that this legislation be extended to include socio-economic status. Improving services for the most disadvantaged groups improves them for everyone. Making services more accessible for the most disadvantaged groups makes services more accessible for everyone e.g. when documents are in larger print most people find them easier to read and there are many people, other than those who use wheelchairs, who find stairs difficult to climb.

General practice in Ireland has traditionally centred on general practitioners who run their practice as independent businesses and have, sometimes, the support of limited administration and, less

often, nursing staff. The recent Irish Primary Care Strategy proposes the development of a more expanded team approach involving GPs working together and joining forces with other staff such as nurses, chiropodists and others to deliver services in an initial ten demonstration primary care teams (see appendix 1). In looking at examples of community development and primary care in Northern Ireland and England, one must remember that in Irish general practice half of practices are single-handed and have limited experience of working together (partly due to concerns about losing patients to each-other). This has improved with co-operation on on-call arrangements, and particularly with the advent of on-call co-operatives.

The Primary Care Strategy, in recommendation 19, states:

*“Mechanisms for active community involvement in primary care teams will be established. Community participation in primary care will be strengthened by encouraging and facilitating the involvement of local communities and voluntary groups in planning and delivery of primary care services. Consumer panels will be convened at regular intervals in each health board. At local level, primary care teams will be encouraged to ensure user participation in service planning and delivery. Consumers will also have an input to needs assessments initiated by individual health boards. A greater input from the community and voluntary sector will enhance the advocacy of primary care teams in ensuring that local and national social and environmental health issues, which influence health, are identified and addressed”.*  
(Department of Health and Children, P 39, 2001)

The National Health Strategy ‘Quality and Fairness’ has equity as one of its fundamental principles:

*“Equity will be central to developing policies (i) to reduce the difference in health status currently running across the social spectrum in Ireland; and (ii) to ensure equitable access to services based on need”.* (Department of Health and Children, 2001, p18)

**The approach to community involvement laid out in the Primary Care Strategy ought to contribute to this pursuit of**

**equity, but this will depend on how community involvement is pursued. To do so, the approach must engage with those experiencing health inequalities and tackle the fundamental causes of those health inequalities. Community development is an approach with a track record for achieving this. Communities must be resourced to participate.**

The Department of Health and Children's most recent Health Promotion Strategy (Department of Health 2000) supported community based approaches to health promotion. The White Paper on a framework for supporting voluntary activity and for developing the relationship between the state and the community and voluntary sector (Dept of Social Community and Family Affairs 2001) states:

*“The Government regards strategic support of the community and voluntary sector as having an importance to the well-being of our society that goes beyond ‘purchase’ of services” (1.5)*

### **The Primary Care Strategy proposals for community involvement**

The Primary Care Strategy and the recent Health Boards Executive community participation guidelines (The Health Boards Executive, 2002) place emphasis on consumer panels as the prime mechanism for involving the community in health service planning. The term consumer suggests an approach involving 'patients' rather than communities and lends itself to the purpose of exploring health service quality issues rather than to investigating community proposals to improve their individual and collective health. This could miss a golden opportunity to try to improve population health in partnership.

How will the panel be constructed? If a formal appointment route is taken as in the English Patient Fora and the Northern Ireland Health and Social Care lay representatives, then those who experience the worst health and perhaps the worst access to health care will not be heard. On the other hand if the panel is constructed through a process of making connections with local groups and individuals and representatives are proposed from the community and report back to it, then the panel would have some legitimacy and be more effective. This would, however, need

support and development and if the panel were to be inclusive, it would require funding for expenses, for interpretation (including sign language), loop systems etc. Its development would require outreach work to ensure hard-to-reach groups are included.

What agenda would be pursued? This is related to the first question. If the agenda is set by the GPs or Health Board, then it may not focus on health inequalities and improving health. Thus, the opportunity to mobilise the communities' own resources to improve community health will be lost. If the agenda is set with the active participation of the community and is broad enough then action to improve health could be achieved.

The consumer panel could easily be marginal to where decisions are made and decision makers must make an explicit link with the panel.

There should be outreach work from the panel to local community groups. The panel could be a democratic model if the participants have access to all necessary information, the individual members are drawn from local community groups (including communities of interest and identity) link to local groups and account to them, a broad agenda is pursued and action results.

In addition to this, or other models of involvement, community development has a key role to play. It should be supported to play a key role in facilitating the active involvement of the most marginalised in health policy and practice and in allowing disadvantaged communities and groups to elaborate and act on their own agendas for change.

## 5. Conclusion

Community development is an effective method for involving local people in creating healthy communities. The commitment to community involvement in the Primary Care Strategy could be effectively realised by adopting a community development approach to developing relationships between local communities and the evolving primary care teams.

Contact between decision-makers in primary care and the community needs to be direct and not through intermediaries (Anderson et al 2002). The most effective way of examining and tackling obstacles to service access suffered by communities experiencing disadvantage and minority groups is in dialogue with them directly. Their involvement will ensure that the energy and commitment to change things and tackle these deep-rooted problems is sustained. In this way, partnerships that include representatives of communities can develop in a way that ensures that the resulting actions will be grounded in the local reality. This will be far more likely to have an impact on the daily lives of the target groups.

General practice populations rarely correspond with natural communities (Neve 1997) and may be too small to relate to communities of interest who may organise city or county-wide. The issue of power and its distribution between general practices (and especially doctors) and local communities must be dealt with (Draper and Hawdon 1998). The dominance of the medical model may hinder community development in primary care (Taylor et al 1998) and one must remember that general practices are focussed on individual illnesses and are in competition with their neighbouring practices (Brown 1994). In working with an individual practice there will be a tension between the practice list and community as locality (Brown 1994). Thus, where practices cover a coherent geographical area or are grouped together, lies the best promise for community development approaches linked to general practice. Why the public is being involved must be clear from the start (Lupton et al 1998).

Having said all of this, a number of the pilot primary care teams named by the Department of Health and Children (appendix 1) cover coherent geographical areas and some represent the amalgamation of a number of existing practices. This offers a clear

opportunity to pursue a community development approach to engaging local communities, both geographical and of identity and interest, with general practice in Ireland. The great unrealised potential in general practice lies in the fact that over 80%-85% of the population visit their GP in any one year (Brown 1999, ICGP 2003). It is a unique public service that connects with the whole community and in this connection lies the potential to tackle many of the key obstacles in the way of creating healthier communities.

Those charged with delivering the Primary Care Strategy should conceive of the ten primary care teams as demonstration sites where small amounts of seed funding can be used to develop a locally sensitive approach to engaging the local communities, employing a community development methodology. Having developed a clear picture of what level of community organisation and networking exists in local communities (including minority communities of interest), a plan should be developed in partnership with local community organisations to build on this existing community infrastructure. A long term commitment must be made to allow time to develop relationships with marginalised communities, based on trust. Dialogue should be encouraged with other areas undertaking similar community participation work. Links should be facilitated eventually between community representatives engaged in similar participation initiatives across the ten primary care teams. Their impact must be maximised by enabling them to collectively have a say at national policy level.

We are at a critical development point for the Irish health services and Primary Care. The opportunity exists to embrace a democratic model where health planning can develop in partnership between those working in general practice and the people that they serve. Community development is an approach that has been tried with success elsewhere and could be adopted in Ireland to involve communities with Primary Care Teams in real ways. The result could be more effective health services, a stronger joint (general practice and community) voice demanding the action needed to tackle health inequality and vibrant communities who are active participants in creating a healthier future.

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**Dr. Philip Crowley**

## Appendix 1

The ten demonstration Primary Care Teams are:

### Virginia, Co. Cavan

A primary care team will be formed, involving a three-GP practice and the health board's community services coming together to deliver services as a team from the new health care unit recently completed in Virginia.

### Lifford, Co. Donegal

The proposal will build on progress already made in Lifford, where there is a four-GP practice operating from a high-quality purpose-built centre, with a range of health and allied professionals providing services from this location.

### Ballymun, Dublin (RAPID area)

A team will be established which will be based in the new civic centre in Ballymun. This will involve local GPs providing services in the new health centre there in partnership with the health board's community services.

### South Inner City, Dublin (part of RAPID area)

A team-based service will be developed through the combining of three GP practices with the community nursing service and other health professionals. It is proposed to refurbish part of the Meath Hospital to serve as a location for the team.

### Dingle Peninsula, Co Kerry

The team will provide services from three locations on the peninsula i.e. Dingle, Castlegregory and Annascaul, from which the seven GPs involved currently provide their services.

### Portarlinton, Co. Laois

One team will be formed, with three GP practices in the town participating. There is space in their existing premises to accommodate the extra personnel who will come to make up the primary care team.

### West County Limerick

This project involves four GPs in Athea, Glin and Foynes, Co. Limerick combining with health board staff serving this community to form a primary care team.

#### Erris Peninsula, Co. Mayo

This project involves establishing a team that, because this is a sparsely populated and disadvantaged rural area, will provide services from a number of locations. Transport links are poor and the Erris Peninsula is included in the CLAR programme for areas of rural disadvantage. The proposed locations for accommodation of the team members are Bangor Erris and Belmullet.

#### Cashel, Co. Tipperary

This proposal involves three GPs in Cashel combining their practices to deliver services in partnership with the other primary care team members. The population to be served will be within the town and its hinterland.

#### Arklow, Co Wicklow

This project involves the establishment of a primary care team to serve the town of Arklow. Nine GPs will combine to deliver services in conjunction with the relevant primary care professionals in the health board community services.

(Department of Health and Children, 2002)

## Appendix 2            Methods of public involvement

There are many methods that can be employed to involve the public or communities in health decision-making and many levels at which one can engage. The following is a summary of both levels and methods that can be used. It is preferable to employ a number of methods rather than to see them as mutually exclusive.

### **Levels of public involvement in health care**

1. *The level of the Health care professional-patient interaction.* Individual and carer involvement in their own care, especially important for parents of small children and patients with long-term illnesses, has been shown to result in better health outcomes (Greenfield).
2. *The level of health service delivery.* User and public involvement in commenting on and improving service quality.
3. *The level of health service planning.* User and public involvement in health policy and service planning.
4. *The level of the community.* Community involvement on their health agenda to improve health.

### **Methods of user participation include:-**

#### **1. Public Meetings**

If there is a major change being planned in service provision the Health Board may hold open public meetings in local meeting places in order to consult the public. In 1994 Liverpool Health Authority held 11 public meetings spending £1260 on publicity and 154 people attended (2-25 people per meeting) and many worked in the health service (Stewart, 1996).

#### **2. Postal Questionnaires and surveys**

Self-completion surveys are the most common method employed and are useful but have some limitations: They are a snapshot of views and they may answer specific questions but offer no opportunity for dialogue or participation in decision-making. The young and working class are least likely to return a survey and they exclude those who have difficulty reading or writing the

language (McIver, 1992). Surveys tell us how many people view a service in a specific way but not WHY.

### **3. Health panels**

Some Health Authorities in the UK set up health panels that are a random selection of households who agree to serve on the panel and who are then surveyed on a regular basis for their views on various topics of interest to the Authority. They often are asked their opinion while being provided with little or no background information. (Pfeffer, 1992) refers to the Health Enquiry and Reinvestment Options exercise in West Glamorgan where the public was asked to evaluate the appropriate level of funding for a range of conditions. Pfeffer felt that respondents were unwittingly involved in a rationing exercise with potentially serious consequences for some groups of patients.

### **4. Focus Groups**

This is an interview using predominantly open questions to ask a group of interviewees about specific situations or events of interest to the researcher (Bryan, p110, 2001). There will be a dialogue and the group may meet once or on a number of occasions. The information that results can be more in-depth than panels or surveys.

### **5. Practice patient participation groups (PPGs)**

A minority of general practices in the UK has set up groups of their patients at the practice to discuss what goes on at the practice with members of staff. The agenda typically includes appointment systems, patient transport etc. and some are self-selecting and some invited. Brown found that PPG participants tended to be unrepresentative of the local population and did not tend to arise in areas of greatest need (Brown, 1999). They are easy to set up but hard to maintain (NHS Alliance, 2002). One study found that participants were mostly older women and from social class 1 and 2 (Agass, 1991)

### **6. Citizens Juries**

The King's Fund in the UK have supported a number of citizens juries to debate and decide specific service issues that have been chosen by the Health Authority or Trust. 4 or 5 members of the public are chosen to sit for 3 or 4 days and they will call expert 'witnesses' to provide information on the topic and eventually come

to a decision on the preferred course of action. This may then be acted on by the authorities. The process costs at least £30,000.

### **7. Rapid Appraisal**

Is a technique whereby a researcher gathers information on the needs of an area by reviewing documents and census information on the area, by observing the area and by interviewing a number of 'key informants' (local workers, shopkeepers, agencies and community 'reps') (Murray, 1995).

**Rapid appraisal and Citizens juries** are exclusive not inclusive, they involve small numbers of people. Citizens Juries involve people in a powerful way in that they can call witnesses and get as much information as they need to make a decision about a service area but they are costly and there is no mechanism for ongoing involvement or ownership in either approach.

### **8. The community rep on committees**

Some decision-making committees have a single community 'rep' on it. They can feel very isolated and struggle to get their perspective heard by the committee.

### **9. Community development approach**

The community is involved from the start and decides for themselves what the priority areas are. They then follow up the issues raised and press for a response or solution.

In many of the approaches that do not specifically involve minority groups, majority views may oppress minority interests.

### **Involving the public/community in health decision-making:**

Different approaches are useful but equally they all have some limitations.

- A number of questions should be asked:
1. Is the approach top-down or bottom-up?
  2. Is it aiming to consult or to involve?
  3. Does the approach allow people to have adequate information to assess the value of a specific service?
  4. Is the agenda set by professionals or by the community?
  5. Are there mechanisms for ensuring views are taken on board, or feeding back to the community?

6. Is the approach likely to involve a reasonable age/gender/race/class spread of participation?

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