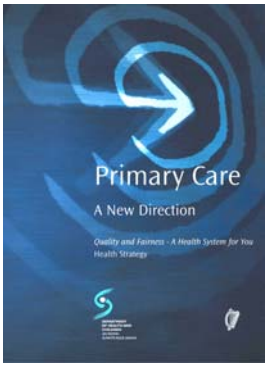
Guidelines for Community Involvement in Health

Position Paper of the National Primary Care Steering Group

December 2004

DEPARTMENT OF HEALTH AND CHILDREN
AN ROINN SLÁINTE AGUS LEANAÍ



Contents **Page**

EXECUTIVE SUMMARY

In 2002 the National Primary Care Steering Group formed the Community Involvement and Health sub-group. The overall objective of this sub-group was:

- to define community involvement in health
- research and review approaches used to effectively engage communities
- show the added value of community involvement in health

A workshop was organised to explore these issues and research was carried out on existing community-led models throughout Ireland. This document identifies and collates existing information on policies, definitions, values and principles as well as identifying key enablers.

The aims of community involvement in health are to set up a process whereby the community defines its own health needs, works out how these needs can best be met and collectively decides on a course of action to achieve the desired outcomes.

Community involvement does not occur in a vacuum but is dependent on a number of key values and principles.

A strategic process is needed to ensure that community involvement is actively embedded within corporate strategy and key enablers have been identified to support this process.

Community participation is important for a number of different reasons and offers a range of benefits to individuals, communities, organisations and society as a whole. Community Participation can achieve a more democratic solution; develop a culture of participation; empower people; mobilise resources and energy; result in the development of holistic and integrated approaches/services; ensure the ownership and sustainability of programmes; result in better decisions and more effective and efficient services and improve health outcomes.

Recommendations

- Commitment to prioritising and resourcing 'Community Involvement in Health' as an essential element in all health programmes/actions and services.

- Development of capacity building training courses for both community representatives and health personnel to facilitate the promotion of community participation.

- Develop a code of practice in relation to 'Community Involvement' including definitions, values, principles and processes.

- Adaptation of appropriate models to facilitate community participation.

- Set up an inclusive process to develop 'Terms of engagement' to inform the partnership process between the community and the health services.

- Develop appropriate 'Performance indicators' to monitor the levels of community involvement in health.

1. BACKGROUND

The principle of 'people-centredness', which is at the heart of the National Health Strategy, is an increasingly important feature of how we plan and deliver services**.** Community involvement is an essential component of a more responsive and appropriate system of health, which is truly people-centred.

The current process of health reform is an excellent opportunity to contribute constructively to this process by building on the recommendations promoting community participation/involvement/engagement which were outlined in key strategic documents e.g. The Health Strategy – *Quality and Fairness A Health System for You* (see Appendix 1). We have drawn on the expertise of the Community Involvement and Health sub-group (CIH) of the National Primary Care Steering Group, the knowledge gained to date from our literature review, our workshop process and our commissioned research on models of good practice, to prepare this submission to the Interim Health Service Executive on our findings and recommendations for consideration.

> *"Keeping people at the centre of care means that you must start with needs assessment and link planning of services to funding and activity."*
>
> Micheál Martin, T.D. Minister for Health and Children, 2003

2. INTRODUCTION

At the 2002 primary care conference in Galway, it was clear that participants were committed to engaging communities, but were unsure how it would apply in an Irish context. They felt they needed clarity on:

- Definitions of Community Involvement
- Approaches used to effectively engage communities
- The added value of community involvement to health

A workshop was organised to explore these issues and to present models of good practice. The case-studies presented were community-led models, and it was recognised that further research was required to explore the application of such models in the health system.

The research found a large range of effective models. They often exist in isolation and are "pilots", or "add-ons" rather than central to the mainstream health system. It was clearly identified that training and capacity building should take place in both the community and the health system, individual and jointly to move the process on.

Learning from international models indicates the imperative for a national process of developing and adopting standards for community engagement between the State and community and voluntary groups.

This document identifies and collates existing information on policies (See appendix 1), definitions, values and principles, as well as identifying key enablers.

3. DEFINITIONS USED IN COMMUNITY INVOLVEMENT:

Terms such as "community involvement", "community development", "community participation" and "community engagement" are used interchangeably in the literature. For the purpose of this document we have selected the following extracts/definitions from the work of the Health Boards Executive (HeBE) document on guidelines for community participation (2002).

"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……."

"…….In developing the health strategy, feedback from the consultation process suggests that patients and clients often have to adapt to the way the system works rather than the system responding to their needs. The consultation process shows that people want to have a say in matters to do with their treatment……."

"…….Community participation can be an effective mechanism to actively seek and listen to the diverse voice of service users……"

"…….It can also enhance local democracy by ensuring that local communities and their representatives have a real say in the delivery of the full range of public services locally."

The aims of community involvement in health are to set up a process whereby the community defines its own health needs, works out how these needs can best be met and collectively decides on a course of action to achieve the desired outcomes. (See Appendix 2 for more details on Community Involvement)

4. VALUES AND PRINCIPLES

Community development does not occur in a vacuum and is dependent on a number of key values and principles.

4.1 Values of community participation

- **Social Justice**: enabling people to claim their human rights, meet their needs and have greater control over the decision-making processes which affect their lives.
- **Participation**: facilitating democratic involvement by people in the issues which affect their lives based on full citizenship, autonomy and shared power, skills, knowledge and experience.
- **Equality:** challenging the attitudes of individuals and the practices of institutions and society, which discriminate against and marginalise people.
- **Learning:** recognise the skills, knowledge and expertise that people contribute and develop by taking action to tackle social, economic, political and environmental problems.
- **Co-operation:** working together to identify and implement action, based on mutual respect of diverse cultures and contributions.

4. 2 Principles of community development

The following principles are taken from Community Participation Guidelines, Health Strategy Implementation Project, The Health Boards Executive, December 2002.

Community development does not occur in a vacuum and is dependent on a number of key principles.

Community development:

- **Is collective -** supporting groups of people to develop knowledge, skills and confidence to engage in collective action. Through their involvement in community activities people learn about skills and resources which they either have or realise they can acquire – that is why the provision of training and support for members of community groups is an important aspect of community development.

- **Is participatory –** actively engaging people in both defining, planning and taking initiatives to respond to health, socio-economic and political problems, with a particular focus on those who are currently most marginalised and excluded from the decision making process.
- **Is empowering –** aiming to effect a sharing of power to create structures which provide genuine participation and involvement.
- **Is task- and process-focussed –** attention paid to both task and process, promoting an inclusive collective process.
- **Is innovative and creative –** it adopts dynamic, innovative and creative approaches to address health, social and economic problems thereby ensuring the participation of local communities.
- **Is focussed on quality of life improvements –** it gains concrete improvements in the quality of life of people by reflecting real needs as identified by local communities.
- **Builds community sector infrastructure –** it recognises the importance of formal and informal support networks in bringing about social change, actively supporting and resourcing the development of such structures.
- **Is committed to equality and ethnic diversity –** it involves strategies which confront prejudice and discrimination on the basis of gender, ethnicity, class, religion, socio-economic status, age, sexuality, skin colour or disability.

5. KEY ENABLERS

A clear sense emerged from speaking to various senior mangers that, unless community involvement was championed at a senior level and actively embedded within corporate strategy, it would remain an add-on and receive neither the commitment nor resources needed.

Research (See appendix 3 for details) also showed that existing projects in Ireland, who have adopted a strategic approach to community involvement, acknowledged that there was a strategic process needed. Key enablers were identified to support this process; these have sub-divided into strategic, task and process enablers.

5.1 Strategic Enablers

- Ensure community involvement is understood and committed to at a corporate strategic level and that it is embedded and sustained in all strategic plans and operational committees.
- Appoint high level sponsor for the committee to mediate, facilitate and broker the committee's progress.
- Involve senior level staff who can champion and direct resources to the committee and ensure a high profile for the group.

5.2 Task and Process Enablers

- Clear terms of reference and ground rules must be jointly agreed.
- Ensure there is absolute clarity on the committee's brief, roles, objectives, expectations, boundaries, work plans etc.
- Ensure clear accountability and transparency.
- Be prepared and able to reorient service/committee/groups to areas of most need which requires flexibility and open mindedness.
- Sub groups of working groups focus energies and sustain commitment if there are clear actions plans and terms of engagement drawn up.
- Structured, rotated and well chaired or facilitated meetings.
- Quick gains of real outcomes help strengthen motivation and commitment.
- Develop a clear vision and understanding of the function of the committee.
- Time and resources for capacity and team building of both staff and service users.
- Democratic, inclusive election process for community representatives.

- Develop common purpose, common language and build a common glossary.
- All members must be viewed as equal partners, respect and openness must be demonstrated by all involved.
- Decision making procedures/styles and criteria (in the case of proposals) must be agreed.
- Devise clear communication and information sharing processes which are continuously evaluated.
- Nurture links with voluntary and community development organisations.
- Outcome-oriented and evidence-based approach.
- Develop / adopt methods that are practical and relevant for all participants.
- Participatory evaluation tools to be used to ensure excluded groups are consulted.

6.0 COMMUNITY INVOLVEMENT IN HEALTH: ADDED VALUE

- Building confidence and self esteem
- Empowerment
- Culture of participation
- Integrated approach
- Ownership and sustainability
- Better decision making
- Capacity building
- Increased opportunities
- Common learning/Joint training
- Development of 'real' partnerships
- Wider agenda setting
- Increased prospects for implementation

7.0 CONCLUSIONS

Community participation is important for a number of different reasons and offers a range of benefits to individuals, communities, organisations and society as a whole. Community Participation can achieve a more democratic solution; develop a culture of participation; empower people; mobilise resources and energy; result in the development of holistic and integrated approaches/services; ensure the ownership and sustainability of programmes; result in better decisions and more effective and efficient services and improve health outcomes. (HeBE 2002)

Glossary

Community Development

Community Development 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. *(Yours Views about Health – Report on Consultation, Health Strategy, 2001)*

Community participation

Community participation is often used interchangeably with, or alongside a number of other terms such as:

Consultation This involves people being referred to for information and asked their opinions. Although it implies that communities' views may be taken into consideration, it has not generally meant that people are actively engaged in the decision-making process.

Involvement this is a term often used synonymously with participation. It implies being included as a necessary part of something.

Empowerment this is a process whereby individuals or communities gain confidence, self – esteem and power to articulate their concerns and ensure that action is taken to address them.

Determinants of health

This is the term used to describe the major factors which influence the health of a population.

Equality

Equality of access, participation and outcomes refers to achieving overall equality between marginalised and non-marginalised groups in terms of access to and distribution of economic, educational, health, cultural, political and other benefits (NESP, l966).

Equity

The word equity relates to the concept of fairness. In WHO terms equity in health implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that one should not be disadvantaged from achieving this potential, if it can be avoided. Based on this definition, the aim of policy for equity and health is not to eliminate all health differences so that everyone has the same level and quality of health but rather to reduce or eliminate those factors that are considered to be both avoidable and unfair.

Whitehead (1992), an international expert on the issue, defines Equity in Health Care as:

Equal access to available care for equal need (in the Irish system this means equal access to public services for equal need).

Equal utilisation for equal need (in practice this would mean monitoring of uptake and supportive action where uptake in noticeably unequal).

Equal quality of care for all (in the Irish system this means in public facilities i.e. public and private patients in public hospitals).

Health

"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". (Department of Health and Children, 2000:5)

Primary Care

Primary care is an approach to care that includes a range of services designed to keep people well, from promotion of health and screening for disease to assessment, diagnosis, treatment and rehabilitation as well as personal social services. The services provide first level contact that is fully accessible by self-referral and have a strong emphasis on working with communities and individuals to improve their health and social well-being. *(Primary Care A New Direction, DoHC 2001)*

Primary Health Care

Primary health care means all the supports and health and personal social services required to promote health, prevent, diagnose and treat illness. It includes General Practice and public health nursing services at its core, and a range of other services, including physiotherapy, occupational therapy, speech and language therapy, psychology, counselling, social work, community pharmacy, drug treatment services, community drug workers, community welfare officers, health promotion officers and community development workers. Primary health care also includes dental, aural and ophthalmic services. International evidence strongly suggests that teamwork among the above disciplines is the most effective way to deliver primary health care.

A distinction is sometimes made between primary health care as a community based participatory approach and primary or medical care as a professional model. In the context of a partnership approach the term primary health care is being used here to denote an inclusive approach which encompasses both. It is recognised that community participation is key to the success of primary health care.

Appendix 1: Health Policy Context

The following section includes direct quotations extracted from recent health policy documents in relation to community engagement.

1.0 Introduction

Since 1986 and the health policy document 'The Health Divide' there has been a commitment in health policies and strategies to facilitate and support the participation of individuals and communities in health care services. This has been endorsed in recent health policy documents, with a clear commitment in the The National Health Strategy 2001: *Quality and Fairness –A Health System for you.*

1.1 The National Health Strategy 2001: *Quality and Fairness –A Health System for you.*

National Goal No: 3 Responsive and Appropriate Care Delivery
OBJECTIVE 1: The Patient is at the centre in the delivery of care

> "Action 52: *Provision will be made for the participation of the community in decisions about the delivery of health and personal social services*".

While there are some community participation initiatives already operating in discrete areas of activity at national and regional level, a more structured approach to community participation is required. Such participation has a number of important advantages. The following actions will be taken:

- Initiatives will be taken to inform and educate the public about the health system including greater communication about the choices and competing priorities which feature in the decision making process.
- Regional Advisory Panels/Co-ordinating Committees (including service providers and consumers) will be established in all health board areas (i) for older consumers and their carers to provide them with a voice and (ii) for people with mental illness to advise on the planning and prioritisation of services, quality of services and promotion of positive mental health initiatives. These committees will be modelled on similar development in the area of disability services and include representation of statutory and voluntary service providers as well as consumers.
- Randomly selected consumer panels will be convened at regular intervals in each health board's areas to allow the public to have their say in health matters that concern them locally.
- A National Consultative Forum will be established to meet on an annual basis to monitor the implementation of the Health Strategy.

To support the implementation of Action 52 the Health Strategy Implementation Project based in the Health Boards Executive have produced a set of 'Community Participation Guidelines (2002) for the health service providers to ensure that the principle of 'people-centredness' which is at the heart of the strategy becomes an increasingly important feature of how services are planned and delivered.

1.2 Primary Care – A New Direction (2001)

Action 19

"Mechanism 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 community and voluntary groups in the 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 environmental health issues, which influence health, are identified and addressed."

1.3 Chief Medical Officer's Report (2001)

"Community Participation in Health has been promoted by the World Health Organisation as an effective means of engaging people in the planning, implementation and evaluation of health care for many decades. In Ireland there is now an increasing acknowledgment and focus on the role of 'community involvement' in health. This is reflected in The Health Strategy 'Quality and Fairness: A Health System for You , which includes people-centredness as one of its four key principles, as well as addressing the manner in which health and social services are delivered in the system. 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. Community Participation is an essential component of a more responsive and appropriate system of care which is truly people-centred."

The CMO's 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."

1.4 Audit of Structures and Functions in the Health System: 2003 (Prospectus Report)

"Keeping people at the centre of care means that you must start with needs assessment and link planning of services to funding and activity."

Micheál Martin, T.D. Minister for Health and Children

1.4.1 The Principles underlying the reform are:

- A new national focus on service delivery and executive management of the system
- A major reduction in fragmentation within the system
- Clear accountability throughout the system
- Improved budgetary and service planning and,
  - ☞ most importantly
- Improved patient care

1.4.2 Problems identified in relation to community involvement:

- Absence of consistent focus on the consumer
- Clear and visible accountability to the user of health services is underdeveloped
- No direct means for local communities to find out what is being planned for their local health services

- No consistent mechanisms for users to feedback their views so as to influence planning decisions

1.4.3 Recommendation 5.3.2

Stakeholder participation needs clearer focus at each level in the system.

- The audit highlights the need for a coherent, system-wide infrastructure for stakeholders partnerships which will link stakeholders into the health system in a meaningful way. The development of these linkages will require the formalisation and extension of models of good practice.
- ERHA/SWAHB 'Community planning for better health' work with community in Clondalkin, designed to transfer skills to allow 'bottom-up' health planning.

1.4.4..Recommendation 1.6: Develop structural mechanisms to increase consumer involvement in decision-making and service delivery.

Steps proposed:

- A forum for formal consultation between the DoHC and other stakeholders on national policy matters.
- Develop structural mechanisms to increase consumer involvement in decision making and service delivery.
- Legislation to provide for consumer representation on the relevant statutory registration bodies to ensure that the views of service users are presented.
- Directly engage citizens and their representatives in needs identification, planning and decision making at appropriate levels.
- The LHO, as one of its central responsibilities, is to have the task of promoting citizens and community participation in its area.
- A national standardised approach to the measurement of patient satisfaction.

1.4.5 Recommendations re: Community Involvement

- Stakeholder partnership, and in particular the participation of individuals and communities in the health system, should not be an 'add-on' to service delivery but an essential means of engaging people as partners with service providers to improve population health.

☞ **The forms of participation should include:**

- Health information and health service information design, delivery and provision to individuals and families.
- Active engagement in community health programmes.
- Feedback mechanisms, complaints procedures and advocacy programmes.
- Opportunities for input into evaluation and monitoring of services.
- Participation in needs identification and service planning at local and regional level.
- Inputs to policy development.
- Extend the remit of the National Consultative Forum to foster increased stakeholder representation and participation in policy-making.

"*In line with our findings that strategic planning and management should not be seen as an ad-hoc function exercised at lengthy intervals, we propose that the National Consultative Forum could serve as a structure through which stakeholders can influence national planning and policy-making on an on-going basis.*"

1.4.6 Potential Existing structures to lobby or link in to:

- National Consultative Forum
- Joint Oireachtas Committee on Health and Children
- Cabinet Committee on the Health Strategy

Appendix 2: Community Involvement

2. Community involvement and its relevance to Health

Terms such as community development, community participation and community involvement/engagement are used interchangeably in the literature. In the context of health it is recommend that you see these terms as progressive, firstly a community development approach is needed to develop peoples capacity to facilitate and enable their participation in projects, this leads to effective community involvement/engagement. For the purpose of this document we have selected the following extracts/definitions from the work of the HeBE document on guidelines on community participation (2001).

2.1 The term community participation can be defined 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……..″*
>
> *"…….In developing the health strategy, feedback from the consultations process suggests that patients and clients often have to adapt to the way the system works rather to the system responding to their needs. The consultation process show that people want to have a say in matters to do with their treatment……..″*
>
> *"……Community participation can be an effective mechanism to actively seek and listen to the diverse voice of service users……″*
>
> *"……It can also enhance local democracy by ensuring that local communities and their representatives have a real say in the delivery of the full range of public services locally.″*

2.2 What is Community Development?

Community Development is both inclusive and collective. In this approach individuals become subjects or participants rather than objects of the exercise. The concern is with collective change in the health status and empowerment of the group as well as addressing the problems of individuals.

The principles which inform community development have to do with participation; empowerment; choice; a belief in the people's capacities to make rational decisions in the circumstances that face them; equality and a rights based approach. Particular priority is given to the most marginalised areas and groups. Community development is underpinned by objectives which are collective, and work which is collective in its planning, in its implementation and in its overall outcome.

> *"Community participation is a programmatic necessity. Without the close involvement of the community, and its families and individuals in health promotion, disease prevention and care of the sick, there is little likelihood that health services will have a durable impact on the health of the community." (WHO)*

The acknowledgment of the importance of paying attention to local people's own perspectives on their health and to understand the impact of the conditions of their lives on their health is essential to community development and to community orientated approaches to primary care.

The WHO sees community participation as an essential way of unlocking valuable knowledge:

> *"With recognition that there is a conventional wisdom in every community, and that people are able to think and act constructively in identifying and solving their own problems, the emphasis is shifting from a medical model to a social model of health which values 'community involvement". (WHO)*

Translated into health the aims of the community development approach are to set up a process whereby the community defines its own health needs, works out how these needs can best be met and collectively decides on a course of action to achieve the desired outcomes.

Participation and involvement are recurrent themes in community development and they are concerned with the collective and active involvement of people in issues that affect their lives. Community Participation in health is viewed as a process through which the community will gain greater control over the social, political, economic and environmental factors that determine their health status.

Community Development aims to empower those living in poverty and or experiencing disadvantage, to bring about change. This 'bottom-up' approach acknowledges that those affected by poverty are often powerless or excluded from participation in society – either because they as individuals have lost confidence, or because prejudice, discrimination, lack of resources or power prevents them. Community development recognises that those who are disadvantaged need support and resources to be empowered and to identify and argue for change to improve their lives and the lives of their communities. Empowering people is, therefore, not just about saying that in principle people have a right to a say in how things are run or decisions that are made. It has to be about transferring power by providing the appropriate resources, support, training and access to information that enable people experiencing disadvantage or poverty to act effectively. (Combat Poverty)

2.3 Towards a meaningful community participation approach to health in Ireland

In response to Action 52 from The National Health Strategy *'Quality and Fairness- A Health System for you'* that provision will be made for the participation of the community in decisions about the delivery of health and personal social services. A set of 'Community Participation Guidelines 2002' have been produced by the Health Boards Executive, Health Strategy Implementation Project for the health service providers to ensure that the principle of 'people-centredness' which is at the heart of the strategy becomes an increasingly important feature of how we plan and deliver services*.*

Community participation is an essential component of a more responsive and appropriate system of care, which is truly people-centred. A number of actions need to be taken to ensure that meaningful community participation in health is established and continues in Ireland. Community participation should occur at a number of different levels, thereby constructively contributing to the:

- Development of health policy
- Identifying and addressing of local health issues
- Implementation of change
- Evaluation of health services

2.3.1 Why is community participation important?

Community participation is important for a number of different reasons and offers a range of benefits to individuals, communities, organisations and society as a whole. Community Participation can achieve a more democratic solution; develop a culture of participation; empower people; mobilise resources and energy; result in the development of holistic and integrated approaches/services; ensure the ownership and sustainability of programmes; result in better decisions and more effective and efficient services and improve health outcomes.

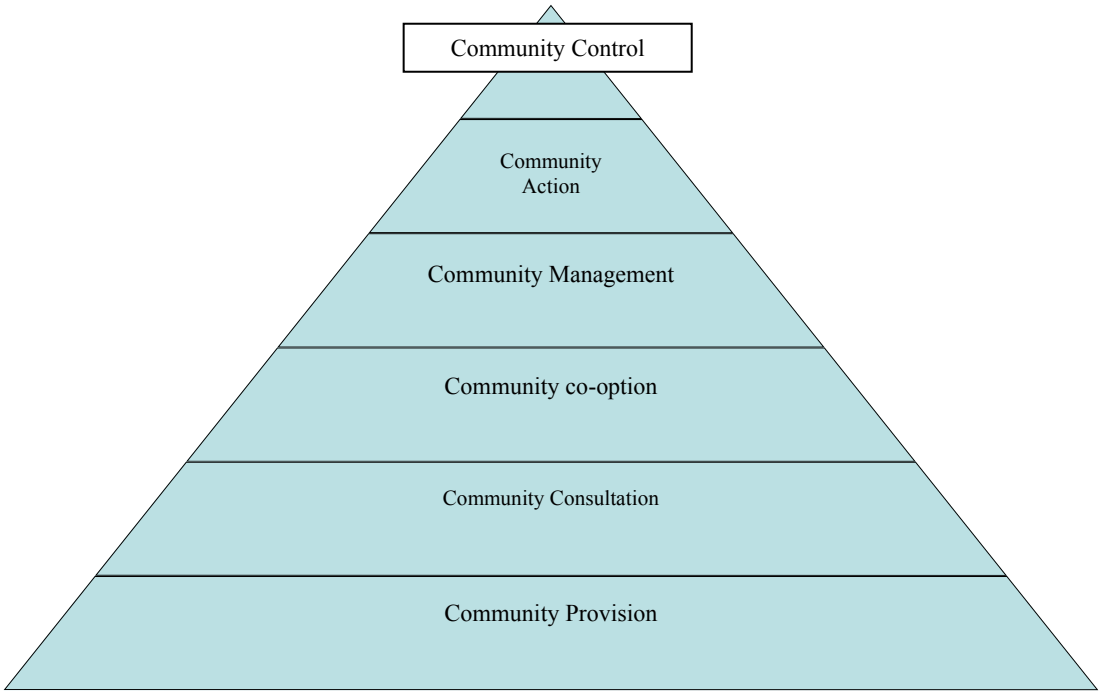
2.3.2 Potential Outcomes (CIH Workshop)

- Building confidence and self esteem
- Empowerment
- Culture of participation
- Integrated approach
- Ownership and sustainability
- Better decision making
- Capacity building
- Increased opportunities
- Common learning/Joint training
- Development of 'real' partnerships
- Wider agenda setting
- Increased prospects for implementation

2.4 Characteristics of a community development approach to health

- 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 communities agendas and it grows and flourishes when communities see changes which they have contributed to.
- It uses existing networks, creates new alliances and uses innovative methods to encourage participation through ensuring accessibility.
- It recognises that those who engage in community development need to understand what it is and be clear about its value.

A Community Development approach takes time, perhaps two or three years, to build up trust, involvement and understanding of local issues and concerns. Undertaking a community profile or needs assessment by involving local people and groups in the process is becoming increasingly popular. This then becomes not only an information-gathering exercise but allows people to learn new skills as well as share experiences. The following pyramid diagram shows a six category classification of CHD activity shown as a continuum with an increasing degree of community influence and control, from the community being provided for, consulted or co-opted at the bottom of the pyramid to devolvement of management with the community taking action and having control at the top.



Implicit in the notion of partnership and collaborations is that the partners and collaborators are equal participants. This process of participation is not the same as the process of consultation where a government agency, local authority or planning group consult with members of the community on an issue which is on their agenda. There is an important distinction to be made between the terms 'participation' and 'consultation'.

Achieving a high degree of participation is very challenging and may sometimes be perceived as a threat to established structures which may lead to resistance to the implicit transference of knowledge and power.

Both professionals and communities bring their own knowledge and ability, and emphasises the need to value and share each other's knowledge. Adams maintains it is essential to discriminate positively to encourage those who are least likely to participate, such as the poor and disadvantaged groups in society. This might involve the allocation of resources such as baby sitting or crèches, travelling expenses, training and administrative help. On the other hand there are several practical and philosophical reasons why it is important to try to increase people's involvement and participation apart from the expressed desire of people to be involved. It:

- Makes for more efficient and cost-effectiveness
- Ensures accountability
- Reflect the democratic ethos of our society
- Encourages people's independence and self-determination
- Is consistent with people's human and civil rights

(Croft and Beresford, 1992)

2.5 Values and Principles of Community Development

Community development does not occur in a vacuum and is dependent on a number of key values and principles.

2.5.1 Values

- **Social Justice**: enabling people to claim their human rights, meet their needs and have greater control over the decision-making processes which affect their lives.
- **Participation**: facilitating democratic involvement by people in the issues which affect their lives based on full citizenship, autonomy and shared power, skills, knowledge and experience.
- **Equality:** challenging the attitudes of individuals and the practices of institutions and society, which discriminate against and marginalise people.
- **Learning:** recognise the skills, knowledge and expertise that people contribute and develop by taking action to tackle social, economic, political and environmental problems.
- **Co-operation:** working together to identify and implement action, based on mutual respect of diverse cultures and contributions.

2.5.2 Principles

- **Is collective -** supporting groups of people to develop knowledge, skills and confidence to engage in collective action. Through their involvement in community activities people learn about skills and resources which they either have or realise they can acquire – that is why the provision of training and support for members of community groups is an important aspect of community development.
- **Is participatory –** actively engaging people in both defining, planning and taking initiatives to respond to health, socio-economic and political problems, with a particular focus on those who are currently most marginalised and excluded from the decision making process.
- **Is empowering –** aiming to effect a sharing of power to create structures which provide genuine participation and involvement.

- **Is task- and process-focussed –** attention paid to both task and process, promoting an inclusive collective process.
- **Is innovative and creative –** it adopts dynamic, innovative and creative approaches to address health, social and economic problems thereby ensuring the participation of local communities.
- **Is focussed on quality of life improvements –** it gains concrete improvements in the quality of life of people by reflecting real needs as identified by local communities.
- **Builds community sector infrastructure –** it recognises the importance of formal and informal support networks in bringing about social change, actively supporting and resourcing the development of such structures.
- **Is committed to equality and ethnic diversity –** it involves strategies which confront prejudice and discrimination on the basis of gender, ethnicity, class, religion, socio-economic status, age, sexuality, skin colour or disability.

2.5.3 Key Principles (Community Involvement in Health Workshop – Oct. 2003)

- Information and language
- Respect
- Dignity
- Continuous and meaningful engagement
- Realistic expectations
- Representative of the diverse voices of the community
- Common understanding
- Effective listening
- Patience
- Broaden and deepen links
- A community's health is about the social determinants of health
- Consultation with communities must be a real process and not tokenism
- Commitment and resources are needed to engage with communities
- Creativity and flexibility are important when sourcing and encouraging communities to engage
- Health providers must move from the medical model to earn communities' respect

Bibliography for Appendix 1 and 2

Community Participation Guidelines, Health Strategy Implementation Project, The Health Boards Executive, December 2002.

The National Health Strategy 2001: *'Quality and Fairness- A Health System for you'* Department of Health and Children.

Department of Health and Children 2001, The National Primary Care Strategy: *Primary Care-A New Direction.*

Department of Health and Children: '*Better Health for Everyone-A Population Health Approach for Ireland'* - Chief Medical Officer's Report 2001.

Audit of Structures and Functions in the Health System: 2003 (Prospectus Report), Department of Health and Children 2003.

The Role of Community Development in Tackling Poverty. Combat Poverty Agency 2000.

Standing Conference for Community Development (SCCD) 1992. *Working Statement on Community Development.*

Quirke B.: *'Future Steps to the Implementation of a Community Development Approach to Health in Ireland.* 2001.

Crowley, P. 2003: *Community Development and Primary Care in Northern Ireland and England.* Combat Poverty Agency.

WHO *Primary Care Towards the Year 2000: A Report of the Consultative Committee on Primary Health Care Development*. Geneva April 1990.

Oakely P. *Community Involvement in health development; Examination of critical issues.* Published by WHO Geneva 1989.

WHO Study Group*: Community Involvement in health development; Challenging Health Services.* WHO Technical Report Series 809, Geneva 1991.

Community Development and Health Network: *Policy to Practise training resources book; Using Community Development methods in Health and Social Services*. CDHN 2000.

Ginnety P. *Tools of the trade: A toolkit for those using community development approaches to health and social wellbeing*. Community Development and Health Network, Northern Ireland 2001.

Quirke B, Sinclair H, and Kevany J. :*Community Participation in Primary Health Care.* Administration, Vol. 42, no.2, p170-182. 1994.

Community Scotland 2004: National standards for community engagement-Pilot Draft**.** www.communitiesscotland.gov.uk.

Mort M, and Kashefi E, 2001*:Grounded Citizens' Juries: a tool for health improvement* Institute for Health Research, Lancaster University*.*

Eastern Regional Health Authority: *Stepping Forward-A Guide to Local Needs Assessment* – Working Document 2004.

Appendix 3:

Report on
Models of Good Practice for
Community Involvement in Health – Irish Context
for the
Community Involvement and Health Sub-Group
of the National Primary Care Steering Group

Audry Deane MBA
December 2004

Contents	Page

Rationale for Report

In October 2003 a workshop organised by the Community Involvement and Health Sub-Group of the National Primary Care Steering Group identified the need from those involved in the initial implementation projects to build on good practice for real community involvement in the design, provision and evaluation of primary care services. A need for information on what constitutes good practice in the Irish context was clearly articulated. A request was made to document and analyse examples of good practice, and also less successful processes, so that learning could be captured and used by the Primary Care Implementation Projects. This desire to capture and share learning dovetails neatly with Action 52 of the Health Strategy which provides for:

> *the participation of the community in decisions about the delivery of health and personal social services*

Action 19 of the Primary Care Strategy also emphasises the

> *the vital role of community involvement and participation in the shaping of local services*

This report sets out to provide these stakeholders with the following:

- An analysis of good practice models where health boards have engaged with communities regarding the design, provision and evaluation of services and the formulation of policy.
- A list of key enablers and successful features of the models which resulted in positive outcomes.
- Identification of barriers to communities' participation in collaborative working with statutory agencies.
- Suggestions on appropriate structures, processes and strategies which facilitate community engagement in the design, delivery and evaluation of health related statutory services.

Methodology

A qualitative approach was decided upon as it allowed the researcher to explore the 'how' of a particular initiative or process and why it was or was not successful rather than the outcomes or results. A quantitative approach was eschewed as this would have required the use of predetermined standardised measures such as surveys or questionnaires which would not have captured the dynamics and relevant 'soft' information.

The unit of analysis for this research was the actual process, model, committee, initiative or project offered as an example by a health board. Thus the findings focus on what the interventions and processes tell us about good practice. Purposeful sampling was considered appropriate in that every health board was contacted as they were all considered as possible repositories of potentially rich information.

Each health board was written to twice and invited to submit examples of what they considered to be successful initiatives involving communities. Relevant people in each board were then contacted by the researcher for a semi structured interview in which various aspects of the intervention/process they were involved with was explored. Representatives of the communities involved in the processes were also contacted and a similar interview was conducted with these people.

Out of the ten health boards four responded in written form. It is evident from the number of boards which responded that community involvement issues may not enjoy a priority position in each board as yet. All health boards were however contacted directly by the researcher. At times it proved difficult to locate the relevant person to connect with which has some implications for inter and intra board knowledge creation and management.

This research does not claim to be either an exhaustive or definitive list of models of good practice of community involvement in health boards. It has sought to explore the models offered by boards themselves and to share this learning.

Key enablers or success factors have been extracted from the various models of good practice which were reviewed for this report. Instead of generating lists of recommendations under various headings this report identifies successful features of good practice and suggests that they are worth considering. Readers should bear in mind that replicating a model will not necessarily result in success. Often a serendipitous fusion of dynamics, context, funding and external and internal considerations synergise to be successful. Likewise another waiver is proffered cautioning against the 'halo' effect whereby similarly named models or processes are deemed to have the same qualities by mere virtue of having the same title.

Various configurations such as Task Forces, Working and Steering Groups, Consumer Panels, Teams and Service User Groups were encountered in this research. For ease of reading the word committee is used to describe any unit which comprises both statutory and community representatives working together towards a common goal. The words service users denotes community participants in these structures.

Principles and Values

When asked to define community involvement it became clear that the words clearly meant different things to different people depending on their own experience, personal ideology and circumstances. The words are very value laden and as such are open to interpretation at an individual level.

Rather general comments often delivered in a tentative manner included:

Community involvement is still scraping at the surface

It takes time, can't be rushed

Take it at the community's pace

Community involvement in health isn't about medicine

It was easier for those spoken with to express what values should underpin engagement between communities and health boards. The replies were consistent in theme with "respect" the most cited value, followed closely by "empowerment", "dignity" and "listening". Others echoed similar views:

Being open, we don't necessarily know best

Health boards shouldn't set rules and must facilitate others to make things happen

Real empowerment is needed

Be supportive but not paternalistic

There was less clarity regarding what principles should underpin community involvement although the most frequently stated were:

- A community's health is about the social determinants of health
- Consultation with communities must be a real process and not tokenism
- Commitment and resources are needed to engage with communities
- Creativity and flexibility are important when sourcing and encouraging communities to engage
- Health providers must move from the medical model to earn communities' respect

A Strategic Approach to Community Involvement

The Eastern Region Health Authority's (ERHA) approach to ensuring that the voice of service users became an integral part of how the board responded to the challenges of the Primary Care Strategy is a useful process to document. In 2002 the ERHA began to develop an Eastern Region Primary Care Action Plan to drive implementation of the Primary Care Strategy[1]. An integral part of this plan was the involvement of representative bodies and service users. They identified the challenge of ensuring that user participation moved from "mere consultation to actual involvement in determining priorities, assessing needs and decision making[2]." They saw the need for an umbrella infrastructure and process to ensure that they

get the structure and philosophy right from the start

They wanted to achieve a systemic approach to ensuring that service users were involved in the planning, commissioning, monitoring and evaluating of services. A Steering Group was set up of professionals and service users to work through and agree a vision, philosophy, framework and terms of engagement for representative service user participation.

Service Planners involved in the process formed useful insights:

- ✓ There was a significant learning curve for both professionals and service users
- ✓ The process was central and much time was invested in getting it right
- ✓ There was intense capacity building of both staff and users
- ✓ Terms of engagement were drawn up which everyone had to adhere to
- ✓ A small group worked with service users on the terms of engagement to explore and agree how they would work together, what commitments were required from all participants, what reporting back structures were required, what the expectations of roles of group members were, what the group would achieve was clarified, metrics were also agreed
- ✓ Staff involved in the process were encouraged to ensure that every protocol, draft and document they worked on was 'service user proofed' sometimes on a one to one basis to check for understanding. Space and time was given to ensure that this happened throughout the process – there were no shortcuts
- ✓ Behavioural and attitudinal changes were required and achieved to enable the process to be successful

Behavioural and attitudinal change on the part of the professionals involved in the process became apparent. Definite shifts were observed in individuals' style, mindset and use of language. There was an acknowledgement that at times individual health care professionals involved were challenged to move outside their comfort zone. It was clear to those involved that to be effective

The challenges must be found, named and worked through

Real efforts were made to accommodate participants to attend meetings – times were agreed which facilitated maximum attendance and as service user participation in this process was so central to the process the ERHA negotiated with service users' employers so that meetings could be attended.

The following sections divide the various enablers or features of good practice found into natural clusters and the boxes give further detail.

[1] This Action Plan will integrate the findings of six working groups (Needs Assessment, ICT, Human Resources, Service Policy, Integration and Quality.
[2] ERHA Position Paper 2003 *Service user participation in developing an Action Plan towards implementing the Primary Care Strategy.*

Task and Process Enablers

In order to begin the work of the committee or group various task and maintenance enablers must be in place to facilitate all participants to contribute as effectively as they can. Enablers identified include:

- Clear terms of reference must be jointly agreed
- Ensure there is absolute clarity on the committee's brief, objectives, boundaries, work plan etc
- Ensure clear accountability i.e. whose job it is to deliver on stated actions
- Action or business plans create cohesion and a focus for energy
- Be prepared and able to reorient service/committee/group to areas of most need which requires flexibility and open mindedness
- Sub-groups of working groups focus energies and sustain commitment if there are clear action plans and terms of engagement drawn up
- Set clear tasks to maintain motivation and clarity of focus
- Structured well chaired or facilitated meetings
- Quick gains concrete outcomes and help cement motivation and commitment

Clear goal and task setting
The North Western Health Board Children and Young People's Committee began its work by bringing an external facilitator to work with a group of senior professionals in 2002. They prioritised setting up the process of how this committee would work. They focused on producing an operational manual (two staff produced the document with each staged signed off by all committee members) which contained the following: mission, defining principles, objectives, strategy, terms of references, core membership, criteria for decision making, action plan and calendar, job description for facilitators who work with each of the ten sub groups and proposal templates through which local groups can apply for funding. The working groups each develop their own action plans. The committee also has an information strategy for staff, children and parents as a key strategic priority to ensure all stakeholders are informed.

Process Development Enablers

The ERHA process referred to on page five of this document emphasises the centrality of process issues when seeking to involve communities in meaningful partnerships. The following list is a distillation of views offered by both community and statutory sources when asked what constitutes good process for purposes of this research:

- Clarity of roles for committee/group members
- Develop a clear vision and understanding of the function of the committee as this impacts directly on the trust levels – it also helps when managing stakeholder expectations of what the process will deliver
- Bring in external expertise when needed, this may often mean more community representatives for particular issues
- Surface assumptions sooner rather than later for hidden agendas
- Be aware of both 'planting and pruning syndromes' whereby issues disliked by a group either get pruned (i.e. a community does not identify smoking cessation programmes as a priority) or planted (health board wants to initiate smoking cessation programmes) despite opposition
- Capacity building of both staff and service users to find a language and culture that is inclusive
- Sensitive selection of community representatives
- Develop common purpose, common language, vision and build a common glossary
- Prioritise trust building and work at it
- External facilitator can yield high rewards in the set up phase as trust can flourish faster
- All members must be viewed as equal partners
- Decision making procedures/styles and criteria (in the case of proposals) must be agreed

- Easy to understand process for getting items/proposals onto the agenda
- Transparency of committee protocols and procedures
- Rotate chairing and or facilitation of committee meetings and ensure appropriate training is provided
- Respect and openness must be demonstrated by all involved
- Strong transformational leadership essential
- All participants must agree on a shared understanding of what they are trying to achieve
- Invest both time and resources in team building

Terms of engagement for committee members
Prioritise time to agree terms of engagement.
Don't take short cuts or cave into time pressure, don't break the communication loop, do the preparatory work, deliver on commitments made, earn respect, acknowledge the tensions and deal with them - if successful the group will begin to protect itself. 'Developing a truly empowering model of participation requires more time, effort, understanding, resources and vision than most people currently imagine'.

Capacity building
Various good practice models cite the vital importance of high quality training. For example the North Western Health Board Traveller Health Unit provides training so that the traveller representatives on this body are supported by project/development workers who go over minutes and agendas with them and help them develop a collective agenda.
The North Eastern Health Board has provided training on critical appraisal skills for eight consumers to help them become effective consumer representatives for maternity services.

A common theme regarding capacity building training was that both communities and statutory health providers needed training: a need for training on the social model of health, on racism, on structures and ethos of community development work was identified for health providers while it was felt that community representatives often needed training on how health boards operate, their systems, structures, protocols and language.

There was a sense from both inside and outside the health boards that the partnership approach to working may be viewed suspiciously or reluctantly by statutory staff used to a less participative, consultative working environment. It was also noted that communities may also have a very idealistic view of how this will operate with no clear understanding of the regulatory, legal and financial constraints faced by the boards.

Both health professionals and community representatives need to access training on the more tacit facets of partnership work - the key issues of power and knowledge differentials, various education levels, perspectives and experience. Successful outcomes for this type of training would be a willingness to agree common goals, vision, structures and processes for mediating differences and getting the job done.

Below are some examples of partnership working and while in some instances the successful format is replicated in all health boards it should be noted that the committee's existence and structure alone is not a guarantee of success.

Examples of partnership working
North Western Health Board Traveller Health Unit decides on its service plans, reviews and budgets in partnership with the client group.
Southern Health Board Regional Coordinating Committee on Physical and Sensory Disabilities has a partnership approach to planning and development of services.
Public health nurses in the Southern Health Board and NICHE (Northside Initiative Community Health) worked collectively to relocate baby clinics to the NICHE family centre which has had a positive impact on numbers attending.

Empowering and respect in action
The Youth Advocacy Programme within the Galway Community Care Services of the Western Health Board has a model whereby managing challenging behaviour of difficult young people is improved by holding 'wraparound meetings' with families and supporters in peoples' homes with the balance strictly 50:50. This programme also engages and pays friends/neighbours/ family members selected by the family as a champion to advocate on behalf of the young people in the programme in whichever way is appropriate. These champions have access to the young person's care plan and head of department. This programme also has agreed internal service level agreements with other units in the board which is based on a 'no refuse no reject' policy. This promotes equity of access to the service and is viewed positively by service users. Respect and dignity for service users and their families and networks are key principles of how this service operates.

Strategic Intent

A clear sense emerged from speaking to various general managers and directors of care groups that unless community development was championed at a senior level and actively embedded within corporate strategy that it would remain an add-on and not receive either the commitment or resources needed. The following bullets express views on this issue:

- ✓ Ensure community involvement is understood and committed to at a corporate strategic level and that it is embedded in all strategic planning and service plans
- ✓ Corporate commitment and support for the committee must be signaled and explicitly sustained
- ✓ Align committee as closely as possible to most appropriate and relevant high profile strategy(ies)
- ✓ Appoint high level sponsor for the committee to mediate, facilitate and broker the committee's progress
- ✓ Raise community involvement as an ongoing item at heads of service meetings
- ✓ Involve senior level staff who can champion and direct resources to the committee and ensure a high profile for the group
- ✓ Set up an intra-board group at strategic level to champion, to protect, to lobby for, to problem solve, and to promote and to profile the committee. This intra-board group could comprise community services, strategy and planning, finance, general managers and other relevant units i.e. mental health, etc

Structures

There was a sense expressed that at times disadvantaged communities did not have the resources to duplicate their energies on various structures through which they engaged with health services. Common sense and a good knowledge of what resources, linkages and potential exists on the ground were seen as pre-requisites to positive relationships with vulnerable communities. Community development workers were seen as a key success factor in making value adding links to communities.

- Look to local existing structures first to engage with communities
- Build on structures that are already there and working
- Avoid duplicating at local level, if there is already a structure in place do not create another one which can overwhelm and overload committed participants
- Start small at local level and work towards greater engagement on regional level structures

Finding appropriate local level structures of community engagement
The Northern Area Health Board (NAHB) is conducting a study to explore expectations and desires of health centre users regarding the types of services and configuration of services in health centres. The decision to commission this research came from the acknowledgement that health centres are a key location in which service users engage with primary care staff and services and that previously service users had not been proactively engaged with on this issue.

An outcome of this research will be a structure through which service users can continue to be involved with the design and delivery of services from health centres into the future. The NAHB is of the view that the most useful and appropriate level at which to begin to engage service users with health services is at health centre level rather than trying to engage them at a more conceptual and strategic level. There are currently staff groups running in each health centre in the NAHB. The board wants to extend these groups to include a balance of both staff and service users.

Selection of Community Representatives

This is a sensitive issue for service providers who consistently voice the concerns around seeing 'the same old faces' being put forward as community representatives. The issue which surfaces continually relates to the representativeness and appropriateness of the 'usual suspects'.

Research from many quarters reveals that experiencing various forms of disadvantage and exclusion whether it is poor housing, low educational attainment and experience of education, living on low incomes or benefit, being unemployed particularly for an extended period, disability and poor health all preclude many people from acquiring the skills, capacity and self esteem to consider becoming involved in community based activity. This is sometimes why a small core of committed activists becomes visible as they are the voices of marginalised silent communities. This does not mean that they do not represent their communities rather that other individuals need support, encouragement, capacity building and specific skills training to arrive at a place where their confidence allows them to participate.

There was a view expressed that there was a need and obligation on community representatives to ensure that they were as representative as possible while on the other hand health care professionals needed to guard against the 'usual suspects syndrome' and welcome committed activists who by their very role are clearly representative.

- An equitable balance in committee composition must be demonstrated
- An effective balance of statutory and community representatives is key
- Be open to creative methodologies of involving communities
- When attempting to engage individual representatives ask them what they want and attempt to secure it for them if feasible
- Ensure appropriate and adequate resources are available for community representatives to facilitate and sustain their participation (travel, elder/child/ dependent care)
- Seek out appropriate places to engage with users

There are various methods which facilitate communities to engage proactively with health boards so as to stimulate their interest in becoming a representative; the Health Boards Executive lists the following:

- ✓ Focus groups
- ✓ Consultation forums
- ✓ User Advisory Panels
- ✓ Public Meetings
- ✓ Listening surveys
- ✓ Workshops on specific themes
- ✓ Local surveys carried out by local people

- ✓ Semi structured interview with community leaders[3]

Creative tactics to encourage involvement
Innovative tactics can be used to connect with communities and to encourage people to select on to committees. 'Go to where they are; schools, parent and toddler groups, in GP surgeries, in health centres, on queues'. A community health worker in the Cork Health Action Zones initiative went to bingo for a month to foster appropriate links with the community and to build trust.

The Lifford-Castefin Primary Care Implementation Project (PCIP) has discovered that recruiting a community development health worker is an effective way of bridging the gap with excluded communities so as to increase their involvement. They have used two methods of engaging with communities:

1. Focus groups – an effective way of engaging communities and discovering needs
Focus groups have been used intensively to capture a wide swathe of views from the community in particular those most marginalised and least likely to engage with service providers. Sixteen focus groups were held, which while time consuming yielded high quality information. The focus groups also empowered people unused to being part of such a process. Each focus group was written up and brought back to participants for their approval which heightened ownership.

The experience of participating was educational; the community health model resonated for participants in that connections were made between the social determinants of health (housing, income, education, environment, transport, social interactions etc) on people's health status. Awareness of the new structure of the PCIP and the potential for communities to be involved was also raised.

2. Community health forum – a bridge in the community
The PCIP has also begun to develop a community health forum on foot of the 16 focus groups held with the community. The rationale for this forum is to support the involvement of community representatives on the primary care team (PCT) so that its representatives can be competent decision makers, ensure smooth and clear information flow both to the PCT and to the community, and can be active in facilitating the rolling out of partnership initiatives with the PCT. This forum will also ensure against burnout of representatives and neglect of their other responsibilities.

Community Development Workers – Key Players

Most community groups spoken to expressed the clear view that community development workers and more specifically community development health workers were vital components to successful community participation. Having dedicated workers with an accurate on the ground knowledge of the health, social, economic and cultural determinants at play in a locale adds value and depth to the delicate work of successful partnership working.

- Ensure that community development workers salaries are ring-fenced and protected
- Community development workers must have critical mass to be effective and secure positive outcomes
- Community development workers should be involved in health services recruitment activities (i.e. sitting on interview panels and contributing to drawing up job descriptions) when their projects are involved
- Non health board employed community development workers should sit on local board run representative structures such as health centre service user groups etc

[3] HEBE. (2002). *Community Involvement Guidelines: Health Strategy Implementation Project*, Dublin, The Health Boards Executive.

Community workers as key members of participatory structures
The Lifford Castlefin Primary Care Implementation Project has found that invaluable 'soft' information and knowledge gleaned by the researcher employed to work with the community could face possible erosion if the relationships and networks developed are not protected with follow-on work. They have found that it would be more cost effective to have employed a community worker for the primary care team from the outset who will continue to build on, sustain and protect the high degree of trust which has resulted from the community focus groups. They note that the degree of perceived independence of the researcher from the health providers was a key success factor. They consider this independence to be important and recommend serious consideration be given to who the employer of a primary care team community worker should be.

Monitoring and Evaluation

This important aspect of both process and project development did not appear to have been allocated much dedicated time, thinking and resources. Some emphasis had been given, often at a tentative level, to collecting qualitative data on some of the work achieved to date although there was no standard data sets or standardised methods used to collect and analyse information. There was a sense that the area was such a new one that there were no clear and commonly agreed principles or agreement on what methods to use to establish and analyse user feedback. Suggestions for development and improvement included:

- ✓ Develop and adopt metrics that are practical and relevant for all participants
- ✓ Participatory evaluation tools to be used to ensure excluded groups are consulted
- ✓ Committees must be needs led and outcome oriented

Communication and Knowledge Management

The process of conducting the research revealed shortcomings in how some health boards manage their knowledge. The level of tacit knowledge hidden within various divisions varies greatly depending on the capacity and comfort with information and communications technology and also on the dominant culture at local level. Community involvement by its nature is a soft edged phenomenon which can be interpreted differently depending on context, personal ideology and experience. A sense that greater efforts need to be focused on creating a user and staff friendly communication infrastructure both intra and inter the various arms of the health services to enable learning and good practice to be shared was evidenced and various suggestions proffered:

- Ensure that general managers and heads of service hear direct feedback from communities through their representatives thus becoming more visible and accountable
- Devise clear information sharing processes and continually test that they are working
- Clarity is needed for service users as to who is the contact person in the board for information, resources, information etc
- Good information flow into committee members so that informed decision making can occur

Using and communicating knowledge to encourage teamwork
The Northern Area Health Board (NAHB) experienced difficulty encouraging some stakeholders to engage in the roll-out of the Primary Care Strategy. To incentivise and facilitate greater involvement the NAHB conducted a mapping exercise which aims to create a 'real map' where identified core primary care staff work together in clearly defined geographic areas. They have begun the process by mapping the public health nurses geographical patches (which do not correspond to District Electoral Division boundaries) with local GPs who work well together while ensuring an appropriate ratio of both medical card and private patients to ensure an equitable outcome for all patients. They intend to build additional maps for other core primary care staff and layer this information on to this 'virtual team' which will form a building block of the primary care team structure.

Building Links

Despite their invisibility informal networks and links can yield dividends in encouraging communities to engage meaningfully with health services.

- Dedicate time to building and sustaining formal and informal trust and communication networks
- Target appropriate external partners and build coalitions and relationships
- Try to integrate a new initiative into relevant structures as soon as it begins to develop rather than trying to shoe horn it into pre-existing structures when it has grown into a fully functioning project or process
- Create links between existing structures external to health boards such as County Development Boards which can be used to forge awareness of health issues
- Nurture links with voluntary and community development organisations

Outcome oriented and evidenced based approach

- Adopt an outcomes based model
- Use evidence based approach to build up picture of need - listen!
- Map local information, building up aggregate picture of need, ask agencies and groups what they know
- Be open and accept findings of evaluations of process, service etc

Barriers to effective working

Constraints identified covered a variety of topics:

- Turnover in community representatives can lead to a lack of continuity, frustration for other committee members and delays in progress
- Time constraints of committee members and difficulty in setting convenient meeting times
- Ensuring minority groups are represented
- Initial lack of public interest in becoming involved
- Lack of comprehensive needs assessment data
- Some community representatives' lack of understanding of health services structures, regulations and constraints
- Using local facilitators to kick start initiatives can be useful as they are accessable and have local knowledge
- Changing set meeting times and dates can be frustrating
- Community representatives must be supported both logistically as in time, funding to attend and personally – training and capacity building
- Demographics can be unfavourable for reaching into communities i.e. dormitory counties sometimes have little interface with service users
- If there are no groups formed because of the demographics it is difficult to begin the relationship as there are no groups to link with
- Tokenism is 'easy to spot!'

Communication promotes respect
A community based health initiative developed a model for community engagement in health using Participatory Research Action methodologies. They were approached by their health board who worked with them to draw up a proposal which was then taken inside the board. There was no further contact with this community group who lack information on what the progress or status of the proposal is. The group speak of a sense that their work has been taken but they have not been kept in the information and decision making loop. They have a sense of disengagement and disappointment which they feel could be addressed and resolved through clear communication from the health board in question.

When it's good it's like this

"They were up front with us"

"We felt part of a team"

"We were willing to put the work in"

"They went through documents line by line"

"We were given homework! We rose to the challenge"

"Our comments were taken on board"

"Issues were included that we brought to the table"

"The outcome was not just another piece of paper"

"We were treated with respect"

"We enjoyed parity of esteem"

"Meetings were open - everything was discussed including internal tensions in the health board"

"Open discussion nothing hidden"

"Spoken to as equals"

"Our issues were registered in the minutes"

"We knew there was a gap in our knowledge but we were respected anyway"

Bibliography

Consultation and summary report on Lifford/Castlefin Primary Health Care Project. North Western Health Board. 2004.

Cois Abhainn Area Profile to facilitate the Cois Abhainn Primary Health Care Project. T. Haase. 2004.

Primary Care - A New Direction. Department of Health and Children. 2001.

National Primary Care Steering Group Progress Report - Primary Care A New Direction. Department of Health and Children 2004.

Grounded Citizens' Juries: a tool for health improvement (draft). Mort M & Kashefi E. Institute for Health Research. Lancaster University. 2001.

Health Impact Assessment – an introductory paper. Institute of Public Health in Ireland. 2001.

Health Impact Assessment – a practical guidance manual. Institute of Public Health in Ireland. 2003.

Community Participation Guidelines Health Strategy Implementation Project. The Health Boards Executive. 2002.

Interim Report on Implementation of Consumer Panels. North Western Health Board. 2003.

Interim Report to Combat Poverty Agency on Community Participation in Primary Care in Lifford/Castlefin Primary Care Team. March 2004.

Community profiling and needs assessment. Presentation to the Community Research Seminar Tackling Poverty Through Community Research. Mc Cafferty D. Combat Poverty Agency. 2001.

Traveller Health Unit in the Eastern Region Annual Report 1999 – 2000. Murphy. P.

Progress Report Southern Health Board Health Action Zones. 2004.

Promoting women's health: a population investment for Ireland's future. Position paper of the Women's Health Council. 2002.

Review of Barnardos Family Support Project. South Eastern Health Board. 2001.

Service user participation in developing an action plan towards implementing the Primary Care Strategy. Position paper of the Eastern Region Health Authority. 2003.

Singular Responses – summary research report on the needs of single men living on the Dingle Peninsula. Nexus Research Cooperative.
Standards for Community Engagement. (draft). Housing Services Scotland.

Written feedback from Southern Health Board, North Western Health Board, Midland Health Board and North Eastern Health Board on models of good practice in community involvement.

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