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Encouraging Participation in a Community Health Programme

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Abstract

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ENCOURAGING PARTICIPATION IN A COMMUNITY HEALTH PROGRAMME
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There is a strong belief among practitioners and some evidence in the literature of the benefits of community participation; particularly its ability to improve the effectiveness and sustainability of health programmes as well as the health and well-being of those participating. However, when attempting to develop a programme to effectively encourage participation within all aspects of the design and delivery of its services, there is much less evidence to guide the practitioner or policy maker.

This study aims to identify factors which enable and constraints which restrict community participation within a health programme in a regeneration area in the South of England. The study used an action research approach, with seven co-researchers of different seniority levels and a community member. The study was conducted over an 18 month period from February 2004 to July 2005. During this time the co-researchers conducted a reconnaissance phase to better understand the issues affecting participation in the area and inform the subsequent action research cycles. During the cycles, the co-researchers used a variety of qualitative and some quantitative methods to assess the effectiveness of various participation strategies. Data from these two stages of the study were combined with data from the action research sessions and interviews with the co-researchers in order to analyse the overall experience of encouraging participation.

Three main areas of findings emerge from the study data: firstly, the interpretations and motivations for participation from community members and public and voluntary sector staff led to the development of a new dynamic definition of participation as a journey. Secondly, the findings on the success, or otherwise, of interventions to encourage participation have led to the conceptualisation of participation as a system in which all components must be developed in order to progress towards a fully participatory programme. Finally, the longitudinal and in-depth nature of the action research process allowed the emergence of findings on the factors which encourage and conversely, discourage the development of a participatory programme. In particular these focus on the nature of the regeneration area, the level of influence of front-line staff within the organisation, the levels of empathy and professionalism among those working with communities and the extent of organisational commitment to participation.

The critical theories of Habermas (1979; 1987) particularly, the exploration of 'life-worlds', are used as an explanatory framework to help explain the interactions between the community and its organisations highlighted by the findings. This leads to the conclusion that a focus on the technicalities of specific participation techniques is insufficient to encourage participation. Instead there is a need to develop space for participative communication both within organisations, to ensure that power can be devolved and empathetic attitudes developed among staff, and between organisations and their communities through a system of participation. It is only then that communities can start to take control of their own development.

Table of Contents

List of Figures

Acknowledgements

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Abbreviations

AR	Action Research
CI	Confidence Interval
CR	Co-Researcher
CRESR	Centre for Regional Economic and Social Research at Sheffield Hallam University. Responsible for the national evaluation of NDC.
DoH	Department of Health
F/CR	Facilitator/Co-research (the author)
NDC	New Deal for Communities
NHS	National Health Service
NPM	New Public Management
NRU	Neighbourhood Renewal Unit
ODPM	Office of the Deputy Prime Minister
PCG	Primary Care Group (forerunner of PCTs)
PCT	Primary Care Trust
PLA	Participatory Learning and Action (a toolbox of methods for encouraging participants to critically analyse their situations)
PHC	Primary Health Care
SRB	Single Regeneration Budget (area based initiative)
UNDP	United Nations Development Programme
WHO	World Health Organisation

Chapter 1: An Introduction to the Study

1.1. Rationale for the Research

This study analyses the process of encouraging public participation within a community health programme. The early impetus for the study came from a collaboration between the School of Nursing and Midwifery at Southampton University and the local Primary Care Trust (PCT). The initial remit for the study was to conduct an evaluation or possibly a case study or some other form of exploration within the health programmes of a New Deal for Communities (NDC) regeneration area in the region. An advert was placed for a research student to develop and conduct the study as a doctorate; I was fortunate enough to be recruited to the post.

Hence, this study is situated within a community health programme within a New Deal for Communities scheme in the south of England. New Deal for Communities (NDC) is a central government initiative, with the overall aim of reducing inequalities between deprived areas and the rest of England. Initiated in1999 there are now a total of 39 NDC schemes in operation across country. The schemes work closely with statutory and voluntary partners in their areas. Hence under the health theme, NDC works closely with the Primary Care and Hospital Trusts. The research studentship through which this study was conducted was funded by the local Primary Care Trust (PCT). The community health programme in which this study is situated supports families in the area with children from before birth to age 17.

Within the policy environment of both the PCT and NDC, community participation plays an important role. NDC has identified community ownership as an overarching theme to guide all that it does. Primary Care Trusts across England are actively developing channels for public and patient involvement. Despite a policy environment conducive to encouraging public involvement in health and regeneration programmes, making participation a reality in practice remains a challenge. Early discussions with staff and residents from the regeneration area during the design phase of this study highlighted many of these challenges in encouraging participation. Consistently concerns were raised about the limited nature of participation in the programme and many expressed frustration at not knowing what else to do to stimulate participation. A review of the literature, conducted as part of this study (see Chapter 2), highlights how others in both health and regeneration work across the UK also face considerable challenges in not only extending participation to all groups within the community, but also improving the experience of participation for community members including increasing their influence over local decision-making.

During the design phase of the study (which is presented in more detail in Chapter 4) meetings were held with those living and working in the regeneration area. Their concerns shaped both the central question and design of the research. The desire of staff and residents to find out what approaches and strategies could improve both the extent and quality of participation led to an agreement between myself and the staff and residents involved in the regeneration programme on the most suitable research question:

> ***Which factors encourage – and conversely, discourage - the development of a participatory community health programme?***

There were strong feelings among those involved in the regeneration area, particularly the community members that a research approach that focused only extracting data from the community with limited influence on local practice would not be appropriate. We soon agreed that a methodological approach that allowed for an immediate influence on practice and could itself be participatory would be ideal. Furthermore, a review of the literature highlighted a lack of research analysing processes of encouraging participation over time. Action research provides an ideal solution; it allows immediate action and development of the programme built on observation and reflection, whilst also allowing an in-depth analysis of organisational processes over time. Another factor which sealed the decision to use an action research approach for the study was the fact that it could itself be participatory, thus allowing the group of co-researchers to 'practice what they preached' when developing wider participation within the community health programme.

The action research approach used in this study had at its core a group of seven co-researchers. The majority of the co-researchers were health workers from the community health programme, but the group also included the programme coordinator, a community member and myself - the facilitator and researcher. The action research group was active from February 2004 to July 2005.

1.2. Aim and Objectives

During this design process an initial aim and set of objectives were developed for the study. These were then discussed by the action research group in the early sessions of the study. This resulted in some adaptations until the following aim and objectives were agreed on to guide the study:

Aim:

To identify factors which enable and constraints which restrict community participation within a health programme in a regeneration area.

Objectives:

1. **To understand the meanings and motivations for participation from the perspectives of agency staff and community members.**

2. **To assess the effectiveness of various action strategies in improving the extent and quality of participation from the perspectives of community members and programme staff.**

3. **To explore the value and effectiveness of techniques to measure participation.**

4. **To analyse the experiences of a team of co-researchers in their efforts to encourage participation.**

5. **To share the experiences, lessons learnt and findings from the study with others in the regeneration and health programmes.**

Further details of the development of the aim, objectives and design of the study are given in Chapter 4.

1.3. A Personal Journey

In order to understand the influences on this study, it is helpful to present my own perspective and the experiences I have had which led to my work on this action research study. Although my work has been supervised through the School of Nursing and Midwifery and the study was based in a community health programme with community health workers, my own background is not as a health worker but instead within community development. Furthermore, most of my work has been with communities in East and West Africa; this is the first piece of work I have conducted in the UK and within the UK health sector.

My experience has been with both non-governmental and government sectors in developing countries and has involved much work with community organisations, particularly in the response to HIV and AIDS. Through these experiences I have been able to work with some truly inspirational community workers and have seen how powerful participation approaches can be. Through a long-term process of careful facilitation drawing on a variety of community participation techniques (particularly the Participatory Learning and Action techniques described in Chapter 2, section 2.9.) communities I have worked with have developed strong and sustainable organisations capable of driving development in their own communities.

It must be emphasised that these communities are inevitable working with very limited resources, low education levels and furthermore, the stigma and discrimination that goes hand in hand with HIV/AIDS has caused suspicion and divisions among community members. My assumption had always been that encouraging community participation in the UK with comparatively abundant resources, strong state structures and well-educated communities could only be more straightforward.

With hindsight, this seems a somewhat naïve view. However, it was this belief in the value of participation to developing confident, empowered communities keen to drive forward their own development that led me to apply for the research studentship to work in the regeneration area. The commitment of both the PCT and the NDC scheme to participation, displayed in part by the inclusion of one of the regeneration area's residents on the interview panel for the post, sealed my enthusiasm to work on the project. Throughout the study my own ideas about participation have continually been challenged, but my belief in the power of participation to transform communities and the organisations that work with them has helped to maintain my motivation during the study.

1.4. Thesis Structure

Action research, with its characteristically emergent form, presents the writer with a variety of presentational options; this has led to a unique structure for this thesis. In particular it should be noted that the design, experience and nature of the action research in practice are given in the first findings chapter, Chapter 4. This reflects the fact that while I, as researcher/facilitator, played a lead role in determining the design of the study, the precise process of the study emerged after detailed discussions and iterations among the co-researchers and remained flexible to respond to the both the action and research needs of the community, the programme and the study itself.

Similarly a detailed description of the context of the programme and the area in which the study were conducted is presented not in this introductory chapter, but in Chapter 5. This reflects how a more in-depth understanding of the programme, the wider regeneration scheme and the area itself developed over the 18 months of the study. This emergent understanding of the context then fed-into the design of the study and the action plans devised by the co-researchers. By presenting this detailed context it is hoped that the reader will be able to judge for themselves the transferability of the findings to their own contexts.

More conventionally, a review of the literature is given in Chapter 2. An early appraisal of the literature was conducted before the study field-work began; this allowed the findings of the review to inform the discussion and reflections of the co-researchers, particularly in the initial sessions of the action research group. More recent material has been added to the review to assist with the discussion of the findings and to benefit from recently published research on regeneration initiatives in the UK.

The literature review begins by exploring the different perspectives on the definition of participation. These definitions were of great help in the development of the co-researchers thinking. However they were felt to be somewhat rigid to define the experience of participation in the study area. Hence the reflections of co-researchers, and others, on the meaning of participation are given in Chapter 5. It is here that the first articulation of participation as a journey is given; this is further explored in the discussion chapter and this definition of participation as a journey is finally summarised in the Chapter 9, the study conclusions.

The literature review, Chapter 2, also assesses the evidence that participation improves the health and well-being of individuals and the effectiveness of health and development programmes. The policy developments that have paved the way for the focus on participation are explored followed by an assessment of the extent and quality of participation within current health and regeneration schemes. Finally in order to inform the participation strategies devised and assessed by the co-researchers, the approaches to participation discussed in the literature are reviewed.

Chapter 3 provides a discussion of the methodology used in the study - action research. As a research approach, action research has been used in many different disciplines in a wide variety of ways; in light of this the chapter begins with an overview of the typology of action research and a discussion of its key characteristics. Understanding the ontological and epistemological groundings of action research is the foundation of designing and conducting an action research study, hence a discussion of these is given. The final sections of the chapter look in detail at the practice of action research, drawing out key ideas on how to conduct such a study, this includes a discussion of the concepts of validity and rigour as well as ethical considerations within action research studies. One interesting feature of this study was the desire by both the co-researchers and the partner organisations involved in the regeneration area to explore the possibilities of measuring any changes in participation levels during the course of the study. The final section of Chapter 3 discusses the issues provoked by the concept of measuring participation and draws on the literature available to inform the co-researchers in their attempts to measure changes in participation in practice.

The following four chapters present different elements of the study's findings. As describe above, Chapter 4 looks at the application of the action research approach in practice, documenting the experience of each phase of the study, from the initial reconnaissance phase, through to the details of the action research cycles and the final observation stage. The analysis process is explained, providing details of the differing approaches used throughout the study. Finally the co-researchers' reflections on the experience of being involved in the study are presented along with my own reflections on my role within the group.

The remaining findings chapters are structured around three key areas; firstly, Chapter 5 presents the contextual environment of the community health programme, followed by the findings on the interpretations and motivations for participation from the perspectives of community members and agency staff. Secondly, in Chapter 6, the details of techniques tried by the co-researchers are given and their success analysed within the context of a wider 'system of participation'. Thirdly, Chapter 7 presents the findings which shed light on underlying constraints and factors which enabled the development of the participation system within a complex partnership of statutory organisations.

Chapter 8 discusses the findings whilst relating them to the research knowledge base. Aspects of critical theory, particularly Habermas' (1987) concept of 'lifeworlds' are drawn on to help explain some of the disjunction between the agencies involved in the regeneration area and the communities they serve. This helps to understand why it can be so challenging to encourage participation in this type of environment. Chapter 9 presents the conclusions highlighting the contribution of the study to the knowledge base and provides recommendations for health and regeneration schemes and for further research.

1.5. Note on Confidentiality and Terminology

Throughout the thesis several terms will be used and it is helpful to explain these at an early stage. Firstly, the term 'agency' is used throughout to describe any statutory or voluntary agency; this includes the NDC scheme, the local authority and the health trusts as well as a number of voluntary organisations.

The co-researchers involved in the action-research ungrudgingly gave considerable time and effort to the implementation of the study. Throughout the action-research sessions they spoke and debated freely. While they have discussed and approved the findings of the study it is only ethical to ensure their identities are kept confidential. In light of this the regeneration area and the community health programme in which the study was located have been anonymised. For simplicity, the community health programme has therefore been termed as 'the programme' throughout this thesis.

Chapter 2: Community Participation: A Literature Review

Over the last decade, community participation has been widely acknowledged by both practitioners and policy makers as a vital component of health and regeneration programmes. Increasingly it is accepted the participation improves the effectiveness, appropriateness and sustainability of health programmes and may also benefit the health and well-being of individuals. Within the field of health, the ascendancy of community participation has its roots in the primary health care (PHC) movement whose defining moment was the signing of the Alma Alta Declaration by WHO member states in 1978. Lack of community participation was given as the key explanation for the low utilisation of services and the poor uptake of health education messages. Increasingly participation was seen as the panacea in a time of shrinking resources, where the contribution of individual communities was vital not only economically but also in fulfilling the rights of all in the community to determine the direction of their own lives. Since 1978, community participation has influenced programme and policy approaches, particularly in developing countries. In the UK, the emphasis on community participation has taken longer to infiltrate mainstream public services. Participation has taken many guises, developing from an approach where the public are seen as consumers with a right to exercise choice over services to a more recent emphasis on the need for community ownership and empowerment.

This literature review explores these different definitions and approaches to community participation and analyses the evidence from the available literature of the benefits of participation for both the individual and the regeneration or health programme. The ideological debates underpinning these different definitions and demands for participation are also explored. In order to set the context surrounding the health and regeneration work in the study area, policy developments in the UK over the last decade are discussed. Then, moving from the rhetoric of policy documents, the literature is reviewed to explore the extent of participation in the UK. Section 9 provides a substantial review of the approaches to participation. Examples and experiences of different approaches are drawn mainly from the UK health and regeneration fields; however these are substantiated with research conducted in other developed and less developed countries to provide lessons from a wider breadth of approaches. The approaches reviewed in this section helped inform the work of the action research group by providing evidence of levels of success in differing circumstances.

2.1. Search Strategy

This literature review is based on searches of Pub Med, the Cochrane Library, BIDS, Science Direct and the Web of Knowledge databases for published research. Searches for grey literature, including documentation of programme experiences and evaluations, were conducted through the Google search facility and through websites of the Joseph Rowntree Foundation, Kings Fund, Department of Health and Office of the Deputy Prime Minister. The terms used during the search, in a number of combinations were; community, participation, user involvement, public participation, social capital and health, empowerment, participation and organisational development, New Deal for Communities and SureStart.

Searching for the term ‘community’ identified literature looking at community participation, empowerment, development, involvement, engagement, consultation and other less well-used terms. This large list of references generated through the search was narrowed down by reading abstracts to determine relevance; priority was given to sourcing findings of primary research and systematic reviews. References from articles accessed during the search were used to find further papers and studies. Studies published before 1985 were excluded from the search, unless they appeared as a key reference whilst reviewing more recent papers. The search excluded non-English language articles; this does place some limitations on the breadth of material reviewed. Priority was given to primary research and systematic reviews of participation experiences and approaches in the UK health and regeneration fields. Some studies from further afield including the US, Australia and less developed countries were included when a lack of research was found from the UK in a particular category. Section 2.2. below provides more details of the body of literature within the various participation categories used in this review.

While the literature search did expose research in the area of patient participation in clinical care, this has was not been reviewed in any depth in this initial review. This decision was taken for several reasons; primarily as experiences and lessons from this area are of an individual clinical nature and may not be of such relevance to the broader issues of community participation for the public good; the motivations for and processes of participation for an individual in their own health care are somewhat different from those which relate to community participation in public health systems and delivery. Ong (in Draper and Hawdon 2000) urges for clarity within the NHS on the distinction between people as patients or ‘users’ and as ‘citizens’. Participating as a patient or user infers a self-interest to improve one’s own health or health care systems, whereas participation as a citizen implies engagement with decision making for the public good. There has been little research that explores the links between these two processes, and there may well be a correlation between being empowered as a patient to take decisions about one’s own health and health care and participating for the wider public good. However, the main focus of the study (and therefore this review) is people’s participation as citizens - working for improvements in health and development that reach beyond their individual clinical care to impact on the lives of the wider community.

2.2. The Literature

Given the current emphasis on community engagement in health there is still a relatively limited body of published research in this area. For example, a review commissioned by the Health Development Agency (Rifkin et al., 2000) of participatory approaches in health identifies a lack of research or even documented experience of programmes and approaches to community participation in health in the UK. This observation is reinforced by the findings of a systematic review conducted by Crawford et al. (2002) which found no studies looking at the effects of participation on the use of services, quality of care, satisfaction or health of patients. This gap in the literature is beginning to fill, particularly as research is conducted within the burgeoning number of regeneration schemes in the UK, many of which emphasise community engagement within their approach. In light of the limitations to the evidence base, the literature included in some of the categories here has been expanded beyond peer-reviewed research on participation within health and regeneration programmes in the UK.

The main bodies of literature that are covered in this review fall into a number of categories. Firstly there are theoretical and conceptual discursive articles exploring the meanings of participation and the ideological perspectives driving the participation agenda. Secondly, the literature assessing the impact of participation on health and community development or regeneration programmes and on an individuals’ health and well-being have been reviewed. Summaries of the two systematic reviews and 17 research papers found that explore these issues are given in a table format in Appendix 1. For each research paper, the table provides details of the research topic, the methodology used, the main findings and a brief critique. Within this category of the literature, few studies of the impact of participation were found from the UK. Hence the search criteria were broadened out to include international studies. This approach solicited further evidence of the impact participation on individual health primarily from the US and on the effectiveness of programmes more internationally. It is interesting to note that within this category of the literature there is a predominance of quantitative studies, particularly epidemiological studies assessing the impact of different dimensions of social capital on morbidity and mortality. Given the ambiguities surrounding the exact impact of participation on both programmes and individuals it is surprising that there are not more qualitative studies able to explore the effects of participation in more depth.

The third category of literature reviewed here is documents and any related conceptual or opinion articles, discussing UK government policy on participation in health and regeneration. Following from this a further category of literature is reviewed to explore the extent and depth of participation within UK health and regeneration programmes. The literature here includes mainly peer-reviewed articles, but as much of the work in this area has been conducted by trusts and foundations, such as the Joseph Rowntree Foundation and the Kings Fund, research and evaluation reports have also been included.

The final category of literature reviewed assesses different approaches to community participation. A summary of the research papers and reports reviewed to shed light on the approaches to participation is given in Appendix 2. This table provides details of the type of approach to participation, the methodology used, key findings and a critique. The literature search for this category on approaches to participation prioritised primary research conducted in the health and regeneration fields in the UK. However, as with the earlier category exploring the extent of participation within the UK, some of the evidence on approaches to participation comes from research and evaluation reports rather than peer-reviewed journal articles. In order to increase the breadth of the review of the approaches to participation, some international experiences have also been included. This is particularly true when looking at approaches that attempt to go beyond consultation and representation to more in-depth processes where members of the community critically analyse their own problems and begin to find and implement their own solutions. This search highlighted few examples of these approaches in the UK, hence experiences from further afield have been drawn on.

Within this category there is a predominance of qualitative studies, with only a couple of mixed method studies, two reviews and one action research study. The lack of quantitative studies may reflect the difficulties in measuring and quantifying participation. It is interesting to note that while there are many action-research studies that use participatory approaches within their own methodological approach, only one action-research study was found by this review that aimed to explore participation within broader programmes and initiatives. This is a limitation in the knowledge base as such studies can help to understand the processes at work within communities or organisations as they attempt to build more participatory practices within their health or development initiatives.

2.3. Defining Participation

One of the first challenges in any literature review of this type is understanding what is meant by participation. As far back as 1969, Arnstein's seminal article expressed concern over the lack of clarity regarding the term 'participation' (Arnstein 1969). She argued that this lead to a range of interpretations and approaches to the concept in practice, many of which fell short of her ideals of participation for citizen control. Her work was based on experiences of urban planning in US and led her to develop one of the first 'ladders of participation'. The ladder depicts a range of interpretations of participation which stretches through degrees of non-participation, to tokenism and to citizen power; an adaptation of this approach is given below:

Rungs on the ladder of participation	**Summary of Arnstein's descriptions of the degrees of citizen power, tokenism and non-participation**	
Citizen control	'have-not' citizens obtain the majority of decision-making seats or full managerial power	Degrees of citizen power
Delegated power		
Partnership	Citizens can negotiate and 'engage in trade-offs' with power-holders	
Placation	A slightly higher degree of tokenism where participants may be asked to advise, but still there is no guarantee that their views will be heeded.	Degrees of tokenism
Consultation	Degrees of tokenism. Participants may hear and be heard but their views not heeded.	
Informing		
Therapy	Describe levels of non-participation. "Their real objective is not to enable people to participate in planning or conducting programs, but to enable power-holders to educate or cure participants." p.217	Degrees of Non-Participation
Manipulation		

Figure 1: Ladder of Participation
(Adapted from Amstein, 1969 p.217)

While some of Amstein's language may appear somewhat outdated – for example describing people as 'have-nots' does not sit well with recent work recognising the strength of communities (Joseph Rowntree Foundation, 2002) – her typology has formed the basis for much contemporary work on participation. A more recent review of participation literature commissioned by UNDP (Clayton et al., 1999) presents very similar categories to Amstein, but places 'partnership' nearer the most participatory end of the ladder and includes an emphasis on equality between the partners. This is reflected in more recent policy developments which encourage the development of partnership working between the statutory, voluntary and private sectors (DoH 1998; DoH 2002). Arnstein's inclusion of 'therapy' with the non-participation category provides an interesting dimension; her article offers a limited explanation of this and concentrates on an example of group therapy being used to placate individuals frustrated with inadequate and unresponsive institutions. Interestingly, more recent discussions of participation do not include an analysis of the participatory or non-participatory nature of therapy.

The UNDP (1999) review sees the ladder of participation as a continuum, with the ultimate aim of achieving self-management. In their analysis, organisations and communities should aim to move from the non-participatory end of the ladder toward the ultimate goal of self-management. In contrast, the development of Amstien's (1969) ladder appears to be more for the purposes of bringing clarity to the analysis of different interpretations of participation used by service providers and planners. Another view holds that communities and the organisations who work with or for them may find different points on the ladder appropriate at different times and to meet different objectives. For example Martin and Boaz (2000) in their evaluation of levels of participation within the Best Value[1] pilot scheme postulate that points on the participation scale can be used as and when they are deemed appropriate to various programme contexts. The authors see different types of participation as equally valid and recommend that they are used as, "appropriate to the service provider's and the consultee's objectives, capacity and expectations" (Martin & Boaz, 2000 p.48). This does not imply a continuum working towards the final and ultimate goal of full community control or self-management, but instead indicates a more pragmatic approach to fit with programme needs. Oakley (1989) argues that "no single form of participation is relevant to all situations and also that different forms have profoundly different consequences" (Oakley, 1989 p.9). In light of this, Oakley (1989) urges those involved in community health programmes to first critically examine the concept of participation before attempting its operationalisation.

This sentiment is echoed by Ong (in Draper & Hawdon, 2000) who emphasises the importance of clarity for the NHS in the use of terms to describe different types and levels of community participation. Underlying the different terms and interpretations of participation are fundamental ideological and theoretical differences and it is important not only to be clear about what is meant by participation but also about why participation is desired at all. The following sections explore some of the theoretical and ideological perspectives on participation.

2.4. Participation: a means or an end?

Oakley (1989) sheds some light on these ideological distinctions, by identifying approaches that see participation as a *means* and others where participation is seen as an *end* in itself. Where participation is seen as a means it is "an input required if objectives are to be achieved" (Oakley 1989 p.9). UNDP's (1999) review has attempted to incorporate these distinctions into their policy and programme work and described participation as a *means* as,

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[1] Best Value: Introduced in 2000, best value is a government inspection regime aimed at improving the quality of local government services.

> "a process whereby local people cooperate or collaborate with externally introduced development programmes or projects. In this way participation becomes the means whereby such initiatives can be more effectively implemented" (Clayton et al., 1999 p.4).

In terms of health, this could mean that targets such as immunisation, smoking cessation rates, or even in the long term, infant mortality rates are ameliorated. The participation of the community is seen as an effective vehicle for reaching pre-determined health goals. Oakley (1989) argues that with this approach "the emphasis is on rapid mobilisation, direct involvement in the task on hand and the abandonment of participation once the task has been completed" (Oakley, 1989 p.9).

However, when participation is seen as an *end* in itself the focus of the health programme changes, indeed, "this goal can be expressed as the empowering of people in terms of their acquiring the skills, knowledge and experience to take greater responsibility for their development" (Clayton et al., 1999 p.4). The implication here is that participation is not only a means of attaining the health outcomes of a programme, but enables the empowerment of those participating. Rifkin (2003) traces the emergence of the term 'empowerment' among those working with communities around the world. She identifies a growing unease with approaches that see communities as homogenous. This unease, coupled with a desire to transform broader structural divisions has led to an emphasis on empowerment where "local people would be able to manage their own lives rather than attacking the structures that kept them impoverished" (Rifkin, 2003 p.170). This fits well with Arnstien's (1969) supposition that the top of the participatory ladder is citizen control which necessitates the redistribution of power. She states that,

> "citizen participation is a categorical term for citizen power. It is the redistribution of power that enables the have-not citizens, presently excluded from the political and economic processes to be deliberately included it the future" (Arnstien, 1969 p.216).

This link between participation and empowerment is not always made explicit in the literature; rather, the terms are frequently used interchangeably adding to the difficulties in interpreting them in practice.

Within this process of citizen's attaining power – or empowerment - several authors (Laverack & Labonte 2000; Gibbon 2002) explicitly identify participation as vital component in the journey towards empowerment, or as Laverack and Labonte (2000) elucidate, community participation is,

> "the means by which people experience more control over decisions that influence their health and lives" which leads to, "greater equality in the social relations of power (who has resources, authority, legitimacy or influence)" (Laverack & Labonte, 2000 p.255).

This is an important point in the context of the current study which aims to look at ways of encouraging *participation*, rather than empowerment. Given that this study involved only 18 months of work with a community health programme, any attempt to achieve empowerment would have been overly ambitious. However, this review goes on to explore the link between participation and empowerment in order to glean some insight into whether, and how, such a link operates in practice.

The range of interpretations of participation in practice and the means- or ends-based motivations for participation stem from differing ideological perspectives on participation. The following section explores how these ideological perspectives have influenced both health and development policy and practice.

2.5. Ideological Perspectives on Participation

Over the last few decades several ideological perspectives have dominated debates on participation. These can be divided into three main paradigms, firstly the approach of the 'New Right' where peoples' participation is seen as a means of exercising consumer choice; where community ownership of programmes is necessary to plug the gaps left by 'rolling back the state' (Mayo & Anastacio 1999). Secondly, the New Public Management approach where participation is seen as a means for better achieving targets and efficiency (Rowe & Shepherd 2002) and finally, a liberation perspective where participation is argued to be part of a process in transforming oppressive societies (Freire 1972). However, it should be noted that within policy documentation, these dimensions often overlap and aspects of the three dimensions can be identified running simultaneous in the justifications for using participatory processes.

2.5.1. The New Right: Rolling back the State

In the UK the political ideology of the New Right developed during the 1970s and 1980s out of a growing dissatisfaction with an economy that appeared to be failing due to the dominance of the state. The collapse of the communist states of Eastern Europe and the USSR further fuelled rightwing arguments that the state's role in the economy should be limited. The laissez-faire monetarist economics of Milton Friedman with its emphasis on the value of market forces dominated New Right thinking. During the 1980s the Conservative government under Margaret Thatcher and the Reagan administration in the US provided the opportunity for restructuring of economies to become more market orientated. Such changes were reflected on a global scale as the International Monetary Fund insisted that its' loans and aid to developing countries became dependent on the structural adjustment of their economies to allow market forces a free reign.

In the UK, nationalised industries were privatised and the state provision of health and social support was questioned. The essence of the New Right approach to community is epitomised in Thatcher's words, "there is no such thing as society. There are individual men and women, and there are families. And no government can do anything except through these people, and people must look to themselves first" (Thatcher, 1987). Despite this emphasis on the individual, ideas of community participation and empowerment are an important element within New Right thinking. With a reduced role for the State and a focus on the responsibilities of the individual, it has been argued that the New Right view community empowerment is the ideal solution for reducing dependence on the state. As Mayo points out:

> "Community capacity-building and empowerment had been particularly valued from a market-orientated perspective, for its potential contribution to enhanced cost-effectiveness, promoting economic development and filling the potential gaps that might otherwise emerge in the provision of services as the local state has been rolled back" (Mayo & Anastacio, 1999 p.19).

The New Right argue that as individuals are able to organise themselves for community action, so the individual has greater choice about the services they can access. While such an approach may be attractive in theory, the experience of the 1980s, when inequalities in the UK grew steadily (Mayo & Anastacio 1999; Sassi in Hills and Stewart, 2005), illustrates how communities with low financial, human and social resources are not in a position to organise themselves to deliver services without some external input. It would appear that this ideological approach benefits only the better off in society who are then able to enjoy lower tax rates.

2.5.2. New Public Management: Efficiency and Targets

The approach to participation identified by Oakley (1989) where participation is seen as a 'means' is clearly very attractive to policy makers and practitioners working hard to meet health targets and achieve pre-defined programme outcomes. The influence of the 'participation as a means' argument can be seen in health and development work across the UK. Rowe and Shepherd (2002) explore recent changes in the way public services, particularly the health service, are run and identify a form of 'new public management' (NPM) within the NHS.

> "The NPM approach is concerned with making services more responsive to consumers' needs and preferences, not to secure greater market share but so that public resources are used more efficiently and effectively." And furthermore, that "power is retained by service providers whose motivation to involve the public is driven by their need to increase efficiency by ensuring that services reflect patients' needs more precisely" (Rowe & Shepherd, 2002 p.279).

From their survey of Primary Care Group (PCG) Board members they conclude, "it appears that lay and clinical board members as much as managers have accepted the NPM approach that regards public involvement as a tool for gathering information on patient views to increase the responsiveness of services rather than as a process of empowerment by involving users in decision making" (Rowe & Shepherd, 2002 p.284).

Hence, while this form of participation may result in more effective services, and Section 2.6. reviews the evidence to support this conclusion, the emphasis is not on participation as a step in the direction of empowerment. Questions have been raised about the sustainability of such approaches (Crawford et al. 2002) as community members participate but may not have any control over decisions that are taken, resulting in a sense of disempowerment and a suspicion that participation is sought only to justify awkward decisions to the wider public (Raco, 2000).

2.5.3. Empowerment for Social Change

The work of Paulo Freire, a Brazilian educationalist, has had a great influence on the participation debate, particularly in developing countries. Freire argues in his key work, Pedagogy of the Oppressed (1972) that in order to transform society, so that it is no longer characterised by the destructive dichotomy of oppressor and oppressed, a process of 'conscientisation' is needed. Freire identifies the dominance of the oppressor's reality and the lack of recognition of this situation as a major constraint, "one of the gravest obstacles to the achievement of liberation is that oppressive reality absorbs those within it and thereby acts to submerge men's consciousness" (Freire, 1972 p.27).

Freire argues that the trap into which many liberation processes fall is that when the oppressed are able to fight or find their way out of inequitable situations, they then simply move into a new class of oppressors taking on many of the characteristics of those that went before them. To overcome this never ending repetition of an oppressive society, Freire argues that "the struggle begins with men's recognition that they have been destroyed. Propaganda, management, manipulation – all arms of domination – cannot be the instruments of their re-humanisation" (Freire, 1972 p.44). This line of argument provides a strong critique of the approaches of new public management that see participation as a means for attaining pre-determined programme goals with no emphasis on empowerment of those participating. Freire (1972) instead espouses a process of continual dialogue - based on reflections on reality and actions within reality - that raise the consciousness of both the oppressor and the oppressed to work towards a truly liberated existence.

> "As they attain this knowledge of reality through common reflection and action, they discover themselves as its permanent re-creators. In this way, the presence of the oppressed in the struggle for their liberation will be what it should be: not pseudo-participation, but committed involvement" (Freire, 1972 p.44).

At the heart of Freire's work is the concept of conscientisation which brings together elements of conscience and action within reality and conscience in a process of common reflection (Park in Reason and Bradbury, 2001). Freire's theories of oppression and liberation provide a useful framework through which to consider not only strategies and motivations for encouraging empowering participation but also provide a grounding for participatory action-research (see Chapter 3). Within Freire's theories any processes that are undertaken to achieve pre-determined programme goals are unlikely to facilitate 'conscientisation' of the oppressors and oppressed. Freire's work is also interesting in how it deals with power, rather than seeing power as a zero-sum, something that only one group of people in society can have, Freire argues that 'authentic liberation' can only exist when both the powerless and the powerful have experienced conscientisation and are in dialogue and working together.

While the identification of the ideological and theoretical underpinnings of participation may appear as a somewhat academic exercise, an understanding of these different approaches illuminates and explains many of the different strategies used to encourage participation. Greater clarity by policy makers and practitioners as to their motivation for encouraging participation would help to dispel much of the confusion and contradictory interpretations of participation that can be found in both health and regeneration programmes.

2.6. Evidence of the Power of Participation

While there are clear differences in ideological and theoretical constructs of participation, many assumptions have been made of the benefits that participation brings. This section explores the evidence behind some of these assumptions of the benefits of participation to individuals and to health and development programmes. The first two arguments, that participation improves the health of programmes and of individuals fall within the new public management ideology and are used to justify the implementation of participation within health and development programmes. The final argument is that participation leads to a greater sense of empowerment and can be seen as a mainstay of the empowerment for social change ideology.

2.6.1. Argument 1: Participation Improves Health and Regeneration Programmes.

The argument here is that to deliver effective health care or development programmes they must be grounded in the realities of the lives of the programme's target population. In theory, this not only makes the programme more *effective* in that it is designed to meet the health or development needs as identified by the target population, but it has been argued to make a programme more *sustainable* as local people build a sense of ownership over the programme. Hence, involving local people in designing and implementing a programme can increase its *effectiveness* as the health issues and modes of operation are determined by local realities, such programmes have more chance of meeting their programme objectives as they have local buy-in, so can be expected to be more efficient and finally, developing a sense of local ownership which it is argued, increases chances of sustainability.

From the Alma Alta Declaration made by WHO member states in 1978 to more current policy documentation (DoH, 1998; DoH, 2001; DoH, 2002) these arguments have influenced the thinking of many in the health sector, for example, the 2002 Cross-Cutting Review on Health Inequalities clearly states that, "interventions to improve health work best with pro-active local participation in their design and implementation." (DoH, 2002 p.7) These views are reiterated within Primary Care Groups (now Trusts), where a recent survey of board members found that the majority felt increased lay involvement in the PCGs/PCTs would significantly improve the quality of services provided, making them more responsive and appropriate to users needs (Rowe & Shepherd, 2002).

These arguments can be said to fit within the New Public Management approach as participation is seen as a means for achieving programme goals more effectively, efficiently and sustainably. Such arguments have gained much weight and it is hard to refute their logic. However, in an age driven by evidence-based decision making, it is helpful to explore the boundaries of these arguments through the available research findings. As noted in section 2.2., the quantity and quality of research in this area is limited; many programmes that have facilitated local participation have not been subject to external evaluations or even documented their own programme experiences. Studies that compare similar health or regeneration interventions one with participation and the other without would be of value in giving weight to these arguments, however during this literature review none have as yet been found. While the available evidence is limited it does offer some useful insights into the benefits and challenges of developing greater participation within health programmes.

Evidence for Argument 1: Participation improves programmes

There is some limited evidence from the available research that participatory approaches have, in some circumstances, been able to determine or change the focus of the intervention to be more in line with the concerns of the community thus establishing more effective programmes. Crawford et al (2002) carried out a systematic review of both published and unpublished research looking at the effects of community participation on health programmes. In the 42 research studies that met their criteria, Crawford et al (2002) found some of the most common changes in response to some form of consultation by health services were the development of new or improved information for patients, more accessible services, the commissioning of new services to meet the needs of the community and in two cases, changes in proposals to close hospitals. These add weight to the argument that listening to the community's felt needs can result in a realignment of services to better meet those needs.

The systematic review carried out by Crawford et al. (2002) excluded studies from community development work, however here too there is some evidence of impact. A UK wide study of 12 area-based regeneration initiatives with a substantial youth focus (Fitzpatrick et al. 2000) found that where consultation had been carried out with sufficient mechanisms in place to influence decision making, there was some impact. In two of the area-based initiatives the consultation exercises were used to inform the development of youth centres and other facilities. While the substantive design of these buildings was already set, the views of young people drawn from consultations did influence more specific details of the plans, including the location of one of the buildings and improved disabled access. Fitzpatrick et al. state that this gave young people "a powerful sense of ownership over the facilities" (Fitzpatrick et al., 2000 p.499). Unfortunately limited details of the methodology are presented in Fitzpatrick et al.'s (2000) paper, particularly the degree of immersion of the researchers in the case study area, the approach to analysis and a clear description of who was interviewed and how they were selected. Furthermore, the paper does not include quotations from young people themselves. This makes it difficult to judge whether the opinions expressed of the value of the consultation are those held by young people themselves or are derived from staff involved in the initiative who may well be eager to present the value of such approaches.

However, the same study also cited examples from several regeneration initiatives that had developed quite elaborate consultation methods, such as youth conferences and youth forums, that then had very little or “no tangible impact on regeneration” (Fitzpatrick et al. 2000 p.502) mainly due to a lack of representation, a disconnection with decision making structures and a lack of purpose of the events.

The strategy or approach used by an organisation is clearly influential in determining the effect of participation; the experiences from regeneration initiatives point to the limited potential of relying on consultation alone as a participation strategy. The ineffectiveness of ill-thought through consultation processes in having any impact leaves them open to the accusation that they are merely a mechanisms for rubber-stamping plans that have been agreed upon elsewhere. The effectiveness of approaches is explored in more depth in section 2.9.

In terms of achieving programme goals effectively, there is some evidence from the field of health promotion that community participation can have a beneficial impact on increasing attendance at screening events. Clover et al. (1996) carried out a randomised trial comparing community participation with mass media and GP involvement as strategies for increasing attendance at mamographic screening. They found a significantly higher attendance due to community participation (63% and 51% in the two communities studied) than mass media (34% in both communities). They found however that using a GP to advise women to attend was significantly more effective (68%) in one community than relying on community participation (51%) (Clover et al. 1996). It must be noted that the study used findings from only four communities and few details are given about the characteristics of the communities or the participation approaches used and hence it is hard to reach conclusions about the appropriateness of the participation strategies they describe.

When the programme goal is specific and relatively clear cut, such as increasing attendance at screening sessions, measuring the effectiveness of community participation is more straightforward; observing impact on more complex outcomes is more difficult. During their systematic review, Crawford et al (2002) were unable to find any studies looking at the effects of involvement on other indicators of an effective service, such as the use of services, quality of care, satisfaction or health of patients. A systematic review of user participation in mental health services found several studies where the involvement of users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation (Simpson & House 2002).

The limited evidence in this area is surprising given the emphasis placed on community engagement in the policy arena and does not sit easily with the views of many practitioners that involvement can have positive effects on programme and health outcomes. However, the limited nature of the evidence may have more to do with the problems of carrying out such studies, in particular the difficulties of linking effects to participation alone.

While Crawford et al's (2002) review focused on health programmes, further evidence of the impact of participation can be found in the broader areas of social development, particularly from developing countries where participatory approaches have been utilised and developed by non-governmental and international organisations for many years. The World Bank, not an organisation traditionally associated with community participation, has in the last decade made a significant shift to become an advocate of participation. This policy development was underpinned by a study carried out by Narayan (1995) who systematically analysed the evaluations of 121 completed rural water supply projects in 49 countries. Some of these evaluations followed programmes for 10 years or more. A total of 140 variables were examined and a multivariate regression analysis was used to test the causal links between participation and the identified variables, statistical methods were used to control for 18 other possible determinants of outcomes. Projects were rated for effectiveness and degree of participation; 81% of projects classified as highly participatory were found to be effective, this was 27 times more effective than low participation projects. The areas with particular improvement were the condition of water systems, economic benefits, percentages of target population reached, environmental benefits, equality of access to facilities and the strengthening of individual's and communities' skills and levels of empowerment. These findings led to a conclusion that "beneficiary participation contributed significantly to project effectiveness" (Narayan, 1995 p.1). The challenges in not only measuring these sort of changes in one community project but then comparing across 121 projects must be taken into consideration, however given these constraints the study does provide one of the most comprehensive and systematic explorations of the impact of participation on programme effectiveness.

Interestingly, a telephone survey carried out in San Diego explored the level of impact that those who participate in voluntary organisations to improve their communities felt they had had. Only 16% said they thought they had little or no impact and 33% felt that they had had a significant impact. Those with less education felt their participation had a bigger impact on their communities than those who were better educated (Johnson et al. 2002).

Clearly, such self-reported data may not illuminate levels of impact on programme or health outcomes, but does shed some light on individual's motivations for participation and how these may differ between education levels.

Another area that Crawford et al's (2002) systematic review did find evidence of the effect of participation was on the organisations that have implemented participation strategies. Many of the studies in their review identified changes in organisational culture which have helped to develop more involvement initiatives. This seems to be partly due to changes in staff attitude; many staff in the reviewed studies found the experience of involving users rewarding and this led to the development of more favourable attitudes to involving users in the future.

These findings are echoed by an action-research study carried out by Kennedy (2000) in Liverpool looking at the processes of health promotion work aimed at improving diet and nutrition. The study found that by working with health professionals to reflect on their health promotion practice and encouraging community involvement in identifying their health problems, attitudes towards the value of lay people's knowledge of health problems and their causes began to change. One of the findings of the study was that there was a "process of reorientation experienced by participating health professionals and organisations" (Kennedy, 2001 p.41). This reorientation culminated in the recruitment of lay people as nutrition outreach workers in recognition of their superior understanding of the causes of poor diet among their community. Unfortunately the study does not provide details of how this process of reorientation took place and there is little analysis of which aspects or turns in the action research cycles may have stimulated this reorientation, however the final result of recognition of lay people's expertise in this area indicates that the increased participation of the community did have some influence on an attitudinal shift among staff.

The question of the impact of community participation on the *efficiency* of health programmes has rarely been addressed. In fact the issue of the time and money needed to establish participatory processes is often cited as a constraint within the approach. For example, a recent study by the Audit Commission (2004) into the progress of 39 New Deal for Communities partnerships continually notes the difficulties in balancing the time-consuming processes of community engagement with delivering services. One of the studies in Crawford et al's (2002) systematic review found that community participation had slowed down the decision-making process. No studies that evaluated the cost-effectiveness of participation as a strategy for meeting programme goals could be found. However, some would argue (Lyons et al. 2001) that with the increased sustainability that community participation stimulates the long-term cost benefits of community participation outweigh the short-term financial and time costs.

The argument that community participation helps to develop *sustainable* programmes is based on the assumption that programmes can build the skills and confidence of those who participate within them and thus strengthen community capacity in general as well as that of community organisations. Several studies have identified building individual skills and organisational strength as key effects of participatory programmes (e.g. Crawford et al., 2002; Edmans & Taket, 2001; Lyons et al., 2001; Narayan, 1995). Lyons et al.'s (2001) case studies of 18 community based organisations found a "link between the nature and extent of participation on the one hand and the sustainability of development gains in general and empowerment in particular on the other" (Lyons et al. 2001 p.1248). They argue this link is facilitated by the appropriateness of training, the level of transparency and accountability within local organisations and the level of social mobility in the surrounding community structures.

The research evidence that community participation results in more efficient, effective and sustainable health care is somewhat limited. It would appear that when linked to decision making structures, consultation and participation in programme design can potentially re-orientate programme goals further in line with community needs. There is some evidence that greater levels of participation can build the skills and confidence of individuals and organisations and hence increase the chances of sustainable development. However, there is very limited evidence of the effects of increased participation in decision-making on the overall effectiveness of achieving programme or health outcomes. Crawford et al. (2002) emphasise that the "absence of evidence should not be mistaken for an absence of effect" (Crawford et al. 2002 p.4). The lack of evidence may instead have its roots in the complexities of designing studies that can not only measure participation, but also effectiveness, efficiency and sustainability and then identify causal links between these processes.

2.6.2. Argument 2: Participation Improves an Individual's Health

Beyond the argument that participatory programmes are more likely to be of benefit, there is an argument that for an individual, participation itself has health benefits. In exploring this argument it is helpful to turn to the literature on 'social capital'. The concept of social capital was first articulated by Peirre Bourdieu in the 1970s and further developed by James Coleman. For Coleman social capital is "a resource of individuals that emerges from their social ties" (Portes & Landolt, 1996 p.19) and can be distinguished from financial capital and human capital. Putnam's (1993; 1996) influential work in Italy and the US has placed a greater emphasis on civic engagement in voluntary and community organisations as an important element of social capital. This has resulted in the identification of three components of social capital as: interpersonal trust, civic engagement and norms of reciprocity, i.e. a general expectation that people will behave cooperatively (for example Kawachi et al. 1997; Kennedy & Glass 1999; Campbell & McLean 2002; Hendryx et al. 2002). These three components of social capital have then been used by researchers to test their relationship with morbidity and mortality. The hypothesis here is that high levels of social captial can moderate "the potentially deleterious health effects of psychosocial stress or other health hazards" (House et al., 1988 p.29). Hendryx et al. (2002) add to this the argument that strong social capital, particularly group membership, improves community accountability structures as the community can put pressure on authorities to maintain accessible health care.

Evidence for Argument 2: Participation improves an individual's health

Much of the evidence to support these arguments of the link between social capital and health comes from the US. Epidemiologists have used large scale survey data to analyse the correlation between levels of mortality, morbidity and social capital. This has been measured through survey questions designed to elucidate how specific areas score within the three types of social capital identified above.

One of the first studies in this area was conducted by Kawachi et al. in 1997 using cross-sectional study data from 39 US States. They found that a one unit increment in average per capita group membership was associated with a decline in total age-adjusted mortality of 83.2 deaths per 100,000 person (95% CI 34.2, 132.2) This result remained significant even after adjusting for poverty. A further study by Kawachi et al. in 1999 which this time controlled for individual level factors such as low income, low education and smoking still found that low social capital appears to result in poor health. Looking specifically at the social trust component of social capital, it was found that those living in an area marked by low social trust were 4 times more likely to have poor health compared to those living in a high social trust area. Taking the group membership component of social capital, Kawachi et al. (1999) found that in areas with low group membership 17.5% reported fair to poor health, whereas in areas of high group membership only 11.6% reported fair to poor health. It must be noted that these findings relied on data of self-rated health status so can not be considered as robust as morbidity incidence data.

The link between social capital and access to health care is explored by Hendryx et al. (2002) who also used cross-sectional survey data in the US with self-reported data on access to health. Their findings show clearly that people living in metropolitan areas with higher levels of social capital reported fewer problems accessing health care. Further research conducted by Ahern and Hendryx (2003) has shown that in areas with higher social capital there is a greater trust in physicians ($p<0.0001$) (Ahern & Hendryx 2003). When considering the applicability of these findings for the UK context, it is important to take into consideration the differing health financing mechanisms used in the States where the role of health insurance may well distort levels of trust and access to health.

One important consideration when examining the influence of social capital on health is that these retrospective survey studies can not prove a causal link between poor social capital and ill-health. While there is clearly a relationship between all elements of social capital and health and several of the studies control for possible confounders such as income, education and smoking, a causal link still can not be claimed. In response to these concerns, House et al. (1988) review several prospective studies from the US, Sweden and Finland and find that the social network index used by these studies, which includes group affiliation, to be a "significant predictor of mortality" (House et al. 1988 p.541). They go on to review experimental laboratory data of the effects of the presence of another individual on human and animal behaviour to conclude that, "social relationships, or the relative lack thereof constitute a major risk factor for health – rivalling the effects of well-established health risk factors such as cigarette smoking, blood lipids, obesity and physical activity" (House et al., 1988 p.541).

While the work of House et al. (1988) argues strongly that there is a causal link between social networks and morbidity and mortality, the studies they review do not provide much information as to which elements of social capital – trust, norms of reciprocity or civic engagement have the strongest influence on health. Kawachi et al.'s (1997; 1999) studies do divide out these elements of social capital and it would appear that levels of trust have a more significant impact than civic engagement.

An Australian study by Baum et al. (2000) used a cross-sectional postal self-completed questionnaire to a random sample of 2,542 respondents to determine levels of participation by demographic, socio-economic and health status. Their findings are similar to the US studies by Kawachi et al. (1997; 1999) and show a correlation between participation rates and both mental and physical health. For example of those with self-rated poor mental health 17.3% scored low on the participation index but for those with good mental health only 12.2% scored low. The differences were similar for physical health as 16.9% of those with poor physical health had low-participation rates and only 10.3% of those with good physical health fell within the low-participation category (Baum et al. 2000).

A qualitative study undertaken by Cattel (2001) in two East London estates shines more light on the experiences of those living in areas of low social capital and how this might impact on health. They found that "those with more restricted networks, for example, were more likely to express feelings associated with negative health outcomes" (Cattel, 2001 p.1508). The study also illustrates how becoming involved in community organisations can have a positive impact on health:

> "There were some residents on both estates who described how becoming involved had changed their lives. Their friendship networks had grown, they were enjoying life, and for many, their health and sense of well-being improved also." (Cattel, 2001 p.1509)

None of the above studies differentiate between levels of participation. The quantitative studies define participation as membership of a group, whether it is a voluntary, church, activist or development organisation. This does little to differentiate between members who are highly active and those who are on the periphery. This distinction could more easily be made in qualitative studies, unfortunately Cattel's (2001) study does not follow this line of inquiry and no other studies were found during the literature review that distinguish between levels of participation and their differing impacts on health. The lack of evidence in this area means that it is not possible to conclude what forms of participation are beneficial to health, however, the overall evidence does point to the benefits of building social capital. As one component of social capital, civic engagement may well be an area that lends itself more easily to intervention by both the public and voluntary sectors than the two other components of social capital - social trust and levels of reciprocity. Hence there is a need for future research to focus more on the relationship between different types of participation and health to develop a more in-depth understanding of the processes involved in the link between social capital and health.

2.6.3. Argument 3: Participation Leads to Empowerment

As discussed above, it has been argued that participation can be a first step in the journey towards empowerment and furthermore, that this should be the motivation for encouraging participation within health and development programmes (Freire 1972; Laverack & Labonte 2000; Cornwall & Gaventa 2001; Gibbon 2002). However, it is important not to take this link for granted, particularly as it is used by many of those interested in social capital to explain at least in part, the relationship between social capital and health. It also helps to explore how participation can be empowering and under what circumstance it may not lead to empowerment but instead lead to greater frustration, isolation and disempowerment.

Attempting to find evidence of a link between participation and empowerment is no easy task; primarily as the terms are often used without definition and may even be used interchangeably. However, from the literature that has looked in-depth at the different levels of participation and empowerment, there is some agreement that empowerment involves the building of a sense of agency to enable individuals and communities to exercise greater control over their own lives and resources (Israel et al., 1994; Menon, 1999). The argument here is that participation at whatever level, whether it is merely information sharing, consultation or consensus building can *potentially* lead individuals and communities towards empowerment as all these levels of participation help individuals to feel a greater sense of control over their own lives.

Evidence for Argument 3: Participation leads to empowerment

There has been minimal research exploring these links in depth, however the social capital literature provides a good starting point. Both Cattell's (2001) study in East London and Schulz et al. (1995) argue that attaining a greater sense of control over one's life can boost self-esteem and feelings of well-being. Schulz et al. (1995) in their large survey of 916 households in the Detroit areas found that even when they controlled other variables, "participation in voluntary organisations is uniquely and significantly related to perceived levels of control" (Schulz et al. 1995 p.316) and that there is a "positive correlation between organisational participation and perceived individual and community control" (Schulz et al. 1995 p.323).

However, as the evidence assessed below illustrates often participation that is not linked to decision-making (i.e. some of the bottom rungs of Arnstein's (1969) ladder) has no real impact on the interventions that shape the lives of those participating. In such a situation it is hard to see how participation could still increase a sense of agency or control. Furthermore, Schulz et al.'s (1995) study does not show a causal link between participating in community organisations and increased feelings of control. There is a possibility that those who decide to participate already have a strong sense of control over their lives. For example Higgins' (1999) ethnographic case study of community health planning forums in British Colombia was able to go beyond the variables identified through the survey-based studies and explores the role of empowerment in determining levels of participation. The study highlights how those with a greater self-perception of power and a sense of control together with a sense of community and communion with others are more likely to participate. These findings link well with the work on social capital as these are also wider community characteristics in areas with high levels of social capital (Coleman 1994) and furthermore with work that argues the importance of individual agency in asserting rights to participate (Cornwall & Gaventa 2001).

In summary, there is some limited evidence to support the assertion that participation can improve the effectiveness, efficiency and sustainability of health and development programmes. However, the evidence is limited and it is unclear what processes are at work to effect these changes. The social capital research indicates that there is a strong correlation between areas with low social capital and poor levels of morbidity and mortality, but the evidence that there is a causal link between low social capital and poor health is still rather tenuous. Finally, it would appear that in some circumstances participation can lead to a greater sense of empowerment, although once again a causal link is not obvious as those participating may have been relatively empowered before their involvement began.

The following section explores the policy developments related to participation. Theoretically it could be argued that such policy developments should be based on the evidence of the impacts of participation on the health of individuals, communities and on the success of health and development programmes. However, as we shall see, the ideological approaches identified in section 2.5. seem to have played a greater role in policy development than the evidence identified above.

2.7. Participation and the Policy Arena

The approaches of the Conservative (1979 - 1997) and Labour (1997 – present) governments reflect the different ideological approaches to participation. The thinking of the New Right directed the Conservative administration and emphasised the rolling back of the state to promote non-state provision of services. In 1990 the NHS and Community Care Act proved pivotal in setting down the government's approach to community participation. The Act enabled a shift towards the consumer by encouraging users' and carers' involvement in the process of assessment of services, by requiring social services to consult with users, carers and voluntary organisations during the production of individual care plans and finally, through the introduction of a complaints procedure with independent inspection units with input of lay members (DoH 1990).

While these policy developments can be seen as positive steps toward greater participation of communities, it is important to look at the reforms through the lens of New Right thinking. The emphasis on 'consumers' provides an important key to the differences in policy approaches of the more recent labour government. Where the public are seen as consumers the emphasis is on their participation in voicing concerns over their own care rather than a deeper involvement in the development of broader service provision and policy formulation for the wider community (Cornwall & Gaventa 2001). Furthermore, an emphasis on consumers can easily ignore the concerns of the less-vocal and disempowered as these groups are unlikely to become members of user's groups or make use of complaints procedures (Jewkes & Murcott 1998; Higgins 1999; Hogg & Williamson 2001). This distinction leads Williams (2002) to criticise the reforms under the

Conservative administration, as rather than working towards more fundamental empowerment, particularly of the otherwise socially excluded they were "designed to encourage the participation of users in discussions about how agencies were to meet the central government's agenda" (Williams, 2002 p.2).

In terms of regeneration, in 1988 the Thatcher government produced the first inter-departmental strategy for urban regeneration, the 'Action for Cities White Paper'. In a stark departure from previous community development approaches, emphasis was placed on a business-led agenda, which according to Foley and Martin (2000) "paid scant regard to community needs" (Foley & Martin, 2000 p.480). By the mid-1990s it became clear that the benefits of economic development rarely 'trickled-down' to the poorest neighbourhoods. In response to this, schemes such as The City Challenge, Rural Challenge and Single Regeneration Budget funds were established to bring together public, community and private stakeholders. However, the schemes have been criticised for selecting areas for funding through a competitive bidding process rather than according to levels of socioeconomic deprivation (Foley & Martin 2000). In terms of community participation, the schemes were said to "give a mere presence, rather than a voice" to community members (Cameron and Davoudi 1998 p.250 in Foley & Martin 2000).

The emphasis on users as consumers and the lack of attention paid to socio-economic and health inequalities has to some extent been redressed under the policy developments of New Labour. The Acheson Report (Acheson, 1998) illuminated the extent of health inequalities in the UK and initiated an analysis more conducive to the empowering interpretation of community participation. Rifkin et al. (2000) identify several positive elements of the Acheson Report for community participation; the emphasis on socio-economic models of health, rather than individual behaviour, the recommendations for interventions aimed at the social and community level rather than the individual and the call for tackling inequity, furthermore, participation is identified as one way of achieving this (Rifkin et al., 2000).

This concern for social justice and equity where community participation, particularly of the most disadvantaged communities is an underlying theme in the policy documentation of New Labour. The DoH have published two new targets aimed at reducing health inequalities focusing on reducing disparities in infant mortality and life expectancy (DoH 2003). There is further recognition of the challenges of engaging the socially excluded and this is specifically addressed within the DoH's Patient and Public Involvement document,

> "NHS bodies, staff and health professionals alike, will need to work in partnership with all parts of the local community, not just those groups they have traditionally had links with (important though these are) so that those who have in the past been marginalised or ignored can have a voice" (DoH, 1998 p.1).

This recognition of inequalities in both attaining health and well-being, and in participating in the structures established for the purpose is encouraging. The National Health Service's July 2000 Plan further reinforces the principle of not only patient, but citizen participation, "patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients' needs" (DoH, 2000 p.4). This emphasis on citizens is far from the consumer oriented approach of the New Right; here people are seen not just as individuals exercising their consumer choice, but as citizens influencing the development and review of services for the wider public good.

More recently Ministers have articulated the approach as a 'new localism' (Brown 2003; Milburn 2003). Milburn (2003) argues that we should look beyond the needs of the individual, "the case for localism over uniformity is about shaping services more effectively to tackle health inequalities in our society every bit as much as it is about shaping them to be responsive to the concerns of the individual" (Milburn, 2003 p.4). Primary Care Trusts are seen as a mainstay of this new localism, with their lay board members and commitment to engage communities (Milburn 2003). More recent plans for Patient's Forums which aim "to facilitate and strengthen the patients' voice" (DoH, 2001 p.4) provide further developments in this area.

The New Labour focus on inequalities is strongly illustrated through the area-based regeneration initiatives, such as New Deal for Communities, Health Action Zones, Healthy Living Centres and SureStart to name just a few, that have been developed over the last few years. Such initiatives are an attempt to provide focused support to localities that have been in decline over the last few decades. The National Strategy for Neighbourhood Renewal (Social Exclusion Unit, 2001) sets out the government's regeneration policies and clearly articulates the importance of community involvement,

> "the government is committed to ensuring that communities' needs and priorities are to the fore in neighbourhood renewal and that residents of poor

> neighbourhoods have the tools to get involved in whatever way they want" (Social Exclusion Unit, 2001 p.51).

More recently the Healthcare Commission (2005) has set out 24 core standards against which all NHS bodies, including Primary Care Trusts, will be measured. The standards represent a level of services that all patients and service users should expect from the NHS. Several of these standards relate to elements of participation. The Fourth Domain in the standards is 'patient focus' which includes Core Standard C14:

> "Healthcare organisations have systems in place to ensure that patients, their relatives and carers:
>
> a. have suitable and accessible information about and clear access to, procedures to register formal complaints and feedback on the quality of services
> b. are not discriminated against when complaints are made
> c. are assured that organisations act appropriately on any concerns and, where appropriate, make changes to ensure improvements in service delivery" (Healthcare Commission, 2005 p.19).

And in the Fifth Domain for 'Accessible and Responsive Care' includes Core Standard C17, the emphasis goes beyond patient involvement to address broader community engagement.

> "The views of patients, their careers and others are sought and taken into account in designing, planning, delivering and improving healthcare services" (Healthcare Commission, 2005 p.22).

The justifications for increased community involvement provided by both the Department of Health and the Neighbourhood Renewal Unit (NRU), which has the overall remit for regeneration programmes, are similar in many ways. They both recognise the ability of community involvement to encouraging better decision-making, fostering more effective programme delivery by ensuring relevance, responsiveness and sustainability (NRU, 1999; DoH 2003). More specifically, the DoH further claims that greater local involvement provides better quality and more responsive services, better outcomes of care and better health for the population, a reduction in health inequalities, and a better understanding of why and how local services need to change and develop (DoH 1998).

In this way the emphasis can be seen within the theoretical framework of new public management, where participation is seen as a means to achieving better services and better health outcomes. However, both the regeneration and health policies also emphasise greater local ownership of health services and this suggests a move up the rungs of the participation ladder towards citizen control. However, it is interesting to note that the Healthcare Commission's core standards (2005) do not specify the direct participation of clients and the wider community in decision making, merely that their views are sought and taken into account. This appears to concur with the lack of emphasis in the other health and regeneration policy documentation on any specific aim to work towards empowerment as a goal in itself. The focus is very much on how community members can help improve services rather than how participation can help to empower individuals and communities. This suggests that there has not been an explicit shift to the idea of participation as an end in itself, where, through a process of empowerment - or as Freire (1972) would argue conscientisation - individual, community and structural relationships can be dramatically changed.

It should also be noted that there is frequently a lack of clarity within policy documentation and even subsequent guidance about how community participation can be encouraged within health and regeneration programmes. This can be seen as both an advantage and a disadvantage as it allows those closer to the ground to decide on their approach. Hence, the ideological framework of practitioners and decision-makers within health and regeneration programmes is all important. Given the domination of traditional approaches, where communities are seen as passive recipients of services designed by knowledgeable professionals, this lack of clarity about the motivations and methods for encouraging participation is worrying. However, the current policy environment does allow the space for quite radical approaches to community ownership and empowerment, but it relies on the skills and ideologies of those interpreting the policies to move away from more traditional relationships with communities. The following section documents the development of one of the regeneration schemes with a focus on community participation – the New Deal for Communities – this is also the regeneration scheme in which this study is situated.

2.7.1. New Deal for Communities within the Policy Context

There has been a clear shift in the policy agenda under the Labour government from a consumerist approach to one more focused on equity and participation. The New Deal for Communities (NDC) scheme, managed by the Office of the Deputy Prime Minister (ODPM), fits within this policy agenda. A key part of the rationale behind NDC is the desire to target specific localities with persistent levels of deprivation. The ODPM defines deprived neighbourhoods through the Index of Multiple Deprivation which pulls together measures of income levels, employment, health, education, housing and access to services in each of the 8,414 wards in England (National Audit Office, 2004). Those communities within the lowest 10 per cent of multiple deprivation scores suffer high unemployment, twice as many people on benefits as the national average, three times as many children living in poverty, poor quality and derelict housing and high crime rates (National Audit Office, 2004).

In order to select communities for the NDC scheme, a national bidding process was conducted among the most deprived wards in England. In the selection process the government aimed to ensure that there was a good spread of recipient areas across the country, that their bids clearly set out long-term plans and that there was a 'sensible demarcation of the communities to receive funding' (National Audit Office 2004). Initially launched in 1988 as a 'pathfinder' initiative for the National Strategy for Neighbourhood Renewal (Social Exclusion Unit, 2001) to trial new approaches to cross-sector working, the scheme now includes 39 communities who receive on average £50 million over a 10 year period.

The scheme is funded by the Office of the Deputy Prime Minister and is co-ordinated by the Neighbourhood Renewal Unit, where it is seen as:

> "A key programme in the Government's strategy to tackle multiple deprivation in the most deprived neighbourhoods in the country, giving some of our poorest communities the resources to tackle their problems in an intensive and co-ordinated way. The aim is to bridge the gap between these neighbourhoods and the rest of England" (Neighbourhood Renewal Unit, 2004).

In recognition of the linkages between structural, societal, economic and health issues, each of the schemes includes programmes under five themes. These themes are education, employment, crime, the environment and health. The schemes work closely with local partners including statutory bodies such as the City Council, Primary Care Trusts and voluntary organisations.

Unlike other earlier regeneration schemes, NDC was designed from the outset to stimulate involvement of local residents with the long term aim of building community ownership for the initiatives developed within the scheme (Audit Commission, 2004). This is evident from the key characteristics of NDC as identified by the Neighbourhood Renewal Unit:

- "Long-term commitment to deliver real change. Communities at the heart of this in partnership with key agencies
- Community involvement and ownership
- Joined-up thinking and solutions. Action based on evidence about 'what works' and 'what doesn't."

(Neighbourhood Renewal Unit, 2004)

The section below draws on early evidence of community involvement and participation within the NDC schemes to assess both the breadth and depth of participation. As the study is located within an NDC and PCT partnership, the experience of PCTs in developing more participation processes is also assessed.

2.8. The Extent of Participation in UK Health and Regeneration Schemes

As described above NDC is a relatively new scheme, Primary Care Trusts are also a fairly recent development and certainly their focus on patient and public participation has only really taken form in the last few years. In light of this much of the literature assessing the extent and quality of community participation focuses on the early processes used within these institutions. Studies exploring the impact of participation on individuals, communities or the work and culture of organisations is still hard to come by. Furthermore, due the time lag in publishing research in peer-reviewed journals many of the papers focus on the early development of these institutions. In response, as described in section 2.2., this section also draws on research reports from Trusts and Foundations that have not gone through the rigorous process of peer-review.

Pickard and Smith (2001) drew on an annual tracker survey of a sample (15%) of Primary Care Groups (forerunners of PCTs) stratified by region in 1999 and found very limited attempts at consulting with the public; for example 82% had not produced patient questionnaires and comment forms, 64% had not held public meetings and 70% had no plans to consult patient groups (Pickard & Smith 2001). This resulted in the belief by over half of lay members on the PCG Boards that attempts to consult had not occurred or been ineffective. However, the lay members did feel that PCGs were committed to do so in the future.

Alborz et al. (2002) analysed the data from the 2000 tracker survey and found some improvement within PCT structures for consulting the public, for example 69% of PCG/Ts had written public involvement plans and 81% of PCG/Ts had public involvement working groups, although only 21 % of these had a designated budget and most of these were £5000 or less. It must be recognised that many of these structures and plans were recent developments and this may help to explain why 87% of PCG/T board members believed local communities were largely unaware of the existence of PCG/Ts and 70% commented on weakness of PCG/Ts in consulting (Alborz et al. 2002).

Alborz et al.'s (2002) study also looks at perception of impact, finding that 48% of PCG/T Board members felt that consultation with the wider community had little or no impact on local service delivery and 77% said that it had little or no impact on clinical governance decisions. Furthermore, Milewa et al.'s (2002) study of PCG/Ts and Local Government structures in three UK districts found that, "managers and clinicians within PCGs and PCTs seem, to varying degrees, to be retaining ownership of approaches to public and patient involvement." (Milewa et al. 2002 p.804). They do however, note the potential for change due to the pressure for greater accountability and responsiveness.

More recent evidence of the impact of consultation exercises comes from the twelve research projects synthesised in the 'Health in Partnership' initiative. While several of the research projects found that consultation processes have been able to influence health care decision-making, unfortunately many of the studies give insufficient detail of exactly what changes were made. However one study included in the synthesis by Harrison and

Dowswell (in Farrell, 2004) used a series of interviews, both telephone and face-to-face, to assess the motivations for and extent of public and patient involvement. They found that 30% of PCG/PCTs could identify involvement activities that had resulted in change to policies, plans or health care provision. However, frustratingly, no details of these changes are given.

Moving to the extent of participation within area regeneration initiatives a review of policy documentation identifies a move away from government schemes and agencies as the initiators of public involvement to a recognition of the importance of community initiated action and participation as well as service improvement (Chanan 2002). These positive moves towards the 'citizen control' rungs of the participation ladder found in policy documents seem to be borne out by an increase in community involvement:

> "There is evidence to suggest that in the past ten years and perhaps the past five in particular, there has been a marked increase in community involvement at least of the relatively surface kind" (Chanan, 2002 p.5).

This increase appears to be borne out by the experience of New Deal for Communities schemes. A recent study of NDCs nationwide conducted by the Audit Commission (2004) found several ways that residents had been involved in NDC programmes. These were as representatives on NDC Boards, with more than half of all board directors being residents, and surveys of residents' views. The Commission also draw on the results of a survey of NDC partner organisations to conclude that "NDC partnerships are effective at communicating with and engaging community members" (Audit Commission, 2004 p. 29). However, when looking at the survey results given in the appendix of the report this appears to be a generous interpretation of the findings as the highest percentage (32.5%) of respondents scored NDC as three, the neutral mid-point on the liket scale, for its strength in engaging with the community. Furthermore, these findings do not show the resident's opinion of NDC strength in engaging with their communities. Hence, it seems a little premature to judge the success of NDC in this area.

Certainly other regeneration schemes have identified constraints in engaging communities to facilitate their influence over decisions. Fitzpatrick et al.'s (2000) UK wide study of 12 area-based regeneration initiatives found that, apart from a few specific changes in light of consultation processes, in general there was a lack of structured mechanisms for feeding ideas and concerns into decision-making processes. These findings are mirrored in Australia where Wood's (2002) qualitative research in six neighbourhood regeneration programmes in three regions of Australia found only two of the localities had any direct mechanism through which to feed residents' views from consultation into decision making processes.

An extensive national evaluation of NDCs is currently being conducted by CRESR at Sheffield Hallam University. While it is too early to assess any conclusive findings, the evaluation team produced a 2003/4 annual report. The report draws on a variety of survey and qualitative interviews to assess the views of NDC boards (staff and residents), programme teams and agencies and conclude that,

> "The community has become more involved in a range of Partnership tasks; there is little evidence to indicate any decrease. And there is general agreement that the community has become more involved in certain tasks such as planning and decision making, membership of NDC forums and project design and development rather than, say project monitoring and evaluation" (CRESR, 2004, p.112).

This evidence that community members are becoming more involved in planning and decision-making is encouraging and would seem to indicate that participation is focusing less on 'superficial' forms of consultation and beginning to move towards greater community control of resources and decision making. However, it is also important to note that while the evaluation identifies an increase in community involvement in planning and decision-making, it also identifies decreasing involvement in project design and development, membership of NDC forums, project appraisal and approval, project management and delivery and evaluation. This reduction in engagement in all except planning and decision-making is partly explained by another finding of national evaluation, that a relatively small group of residents are heavily involved in the programme. While their involvement may be increasing as they become more experienced in the ways of NDC, allowing them to get more involved in planning and decision-making, the overall number of residents from across the community that are getting involved in the broader aspects of the programme is not increasing (CRESR, 2004).

It is important to note that this report from the NDC evaluation team draws on interview data from agency and programme staff and members of NDC boards. While the NDC board interviews will have included interviews with resident members of the board, attempts to hear the views of the wider community, have not as yet been included in the evaluation report. According to the evaluation team this new evidence is imminent, in the form of a household survey. However, as it stands it is hard to assess changes in levels of community participation without being able to balance predominantly staff views of participation with that of the wider community.

The NDC national evaluation team have conducted some more specific research exploring community participation from a number of angles, including residents' involvement in housing improvements (Cole et al. 2004), parental involvement in education (Lall et al. 2004) and young people's involvement across NDC (Marshall, 2004). It is important to note that these research reports have not been peer reviewed, however they do give details of fairly robust methodologies. Drawing on household surveys in six case study sites, Marshall (2004) finds that young people's involvement in NDC activities is only 14%, lower than for residents of other ages, 17%. Given this low involvement in activities, it is unsurprising that there is little evidence of greater participation of young people. For example only two out of the six case studies have a forum for youth participation and this is coupled with a low awareness of NDC and its activities in general. Lall et al.'s (2004) study of parental involvement in education conducted case studies of 3 NDC partnerships. Here parental involvement revolves around improved communication between parents and schools and supporting parents to understand their children's course work; this is a slightly different interpretation of participation from approaches which aim to hear community views and build community participation in the design, delivery and evaluation of services. However, an interesting finding of the study is that initiatives aimed at increasing parental involvement in their child's education are more successful when such initiatives have,

> "adopted a bottom-up strategy where problems and needs are identified by local people themselves and involved local people in key project roles" (Lall et al. p.i).

Cole et al. (2004) reviewed all NDC partnership delivery plans, conducted a telephone survey of 10 NDC partnerships and more in-depth case studies with three partnerships using focus groups with residents and interviews with key stakeholders. The resident focus groups consisted of residents that had been heavily involved with housing developments and also those that had been more on the periphery. While the report does not specify how participants were selected, the selection strategy for the focus groups does go some way to hear the views of residents not heavily involved with NDC – something which is currently lacking in much of the NDC evaluation work.

Their study found that in all 10 of the NDC partnerships local residents had been involved in formulating the housing strategy; this involvement centred around three areas; developing a framework for renewal in the area, ratifying a strategy and the application of the plan at local level (Cole et al. 2004). However they also found that relatively few residents had actually been involved in the strategy development and these residents were often involved in other community initiatives or part of the NDC board. This chimes with the findings of the overall national evaluation programme report (2004) that found only a small group of residents to be deeply involved with NDC.

The study further highlights some of the tensions inherent in a process where a small group of residents are asked to take decision for the wider community. For example, when asked to make decisions about the demolition of homes, many residents, "felt uncomfortable making decisions that would affect not only themselves, but the broader resident population" (Cole et al. 2004 p.i). Their study found differing views in terms of the impact of participation on individuals with some feeling empowered and others believing that in reality strategy formation was led by agencies. Again, both staff and residents expressed concern at the limited number of people participating and the limited representation of certain groups in the community.

The limited involvement of the wider community is also identified in Perrons and Skyers' (2003) case study of a London NDC. Their study is based on 45 in-depth interviews with NDC board members, key agency staff, local tenants association and residents. They found that the most common form of participation was consultation, however frequently insufficient time was allowed for consultation exercises and few attempts were made to encourage more isolated groups in the area to participate on any level leading to "uncertainty about the extent to which the desire to recognise and include different groups can be translated into effective representation" (Perrons and Skyers, 2003 p.278). This lack of effective representation raises concerns that "extending governance may simultaneously weaken local democracy by prioritising the interests of those who have the time or inclination to be involved" (Perrons and Skyers, 2003 p.278).

Dinham's (2005) study of an NDC scheme in London clearly highlights the constraints to participation within NDC. Dinham interviewed 30 residents and while few details of the methodology of the study are given, the residents did include a mixture of those that were engaged in the structures of NDC and those that were not. The study offers some valuable insights into residents' perceptions and experiences of NDC. Dinham found that for most residents the elections held for the resident members of the NDC board were the most common form of participation. While residents preferred less formal means of engagement such as community groups and forums, there appears to have been a limited emphasis on these mechanisms with this NDC. Furthermore residents identified a lack of training and support for engaging in the more formal meetings that were more common within NDC structures,

> "Local residents perceived a lack of commitment to or opportunities for training and capacity building for genuine newcomers and many described feelings of inadequacy in formal contexts, especially board meetings" (Dinham, 2005 p.307).

Dinham's (2005) study is helpful in highlighting the limitations to NDC's approach to regeneration; a frustration with his study is that quotations from residents are not presented and details of the analysis process are not given. This leads to a lack of confidence in the credibility of his findings. Furthermore, it must be noted that the study was conducted in only one of the NDC schemes; possibilities of extrapolating these findings to other NDC areas may be limited. However the study does provide helpful insights particularly as it is based on resident interviews rather than interviews with agency staff and those residents already heavily involved in the scheme. In section 2.9. below the details of the constraints within the more specific participation approaches explored by Dinham (2005) are discussed. What is important to note here is the argument that NDC, rather than following the community development approach, has fallen back on traditional bureaucratic structures of local government. This has resulted in the development of a minority of politicised citizens, rather than opportunities for many to begin a 'journey of empowerment' (Dinham, 2005 p.303), leading to the conclusion that within NDC there is an,

> "emphasis on the person as a political citizen, so that the idea of the empowered community is relegated in policy and practice" (Dinham, 2005 p.309).

While the body of research exploring participation within PCT and NDC schemes is still limited, and would benefit greatly from studies exploring more recent approaches at encouraging participation, the available evidence shows that despite attempts being made within PCTs and NDCs to encourage participation, there are many signs of the constraints to encouraging widespread and effective participation. The inability of many participation approaches to include anyone beyond a small group of highly committed residents is worrying. While there seems to be much evidence of consultation within both PCTs and NDC, there are few examples of consultation processes that have been allowed sufficient time to reach more isolated community members and that trigger a process of more in-depth participation, potentially leading to a more empowered community. This is highlighted in the limited channels for consultation findings and processes to influence decision making. These limitations undoubtedly lead to concerns that community participation is being seen as an official requirement to be fulfilled, rather than a process capable of transforming communities so they can take charge of their own development. It is still early days for these structures and processes and it can only be hoped that the lessons learnt from these experiences will build deeper more meaningful participation in the future.

2.9. Approaches to Encouraging Participation

This final section looks in more depth at the approaches to participation described and, to a certain degree, assessed in the literature. Understanding how theses approaches work in practice and the challenges faced in their implementation was crucial information for the action research group. Appreciating the success and pitfalls others had encountered helped the co-researchers in designing participation strategies for use within the Programme. While it is difficult to precisely categorise the approaches to participation, broadly they fall within two groups; a) consultation and b) representation or recurrent participation. Consultation is used here to refer to a number of methods designed to hear the views of users and the general public. Representation and recurrent participation refers to the practice of involving representatives of communities in a variety of organisational structures and the establishment of other forums or groups among community members or users – not necessarily representatives of any wider body - to participate in the service in some way over a period of time.

Some of the participation experiences described and analysed within the literature do not fall neatly into any one of these categories and may show characteristics of more than one group. However, given the co-researchers' aim within this study of encouraging participation, it is helpful to attempt to categorise these different approaches to participation and analyse their successes and constraints. The two approaches are taken in turn to first describe the ways in which they have been used and then to analyse any constraints faced in their use in encouraging participation.

2.9.1. Consultation

Within the literature the approach to participation most commonly discussed is consultation. A variety of methods of consultation are referred to, all of which aim to gather the views of local residents or service users. The different methods vary in terms of their complexity and level of engagement and range from questionnaires and comment forms (Jordan et al. 1998; Anderson and Florin, 2000; Martin and Boaz, 2000; Lowndes et al. 2001; Bagley et al 2004) to more flexible methods such as public meetings, youth forums, focus groups, consultation of local user groups (Martin and Boaz, 2000; Fitzpatrick, et al. 2000; Alborz et al. 2002; Perrons and Skyers 2003) and more in-depth and focused methods for greater deliberation such as citizen juries and participatory needs assessment (Pickard, 1998; Lenaghan, 1999; Woodward, 2000; Cornwall et al. 2003)

As reflected in studies of the Primary Care Trusts and NDC, surveys are consistently identified as the most common form of consultation used in the UK. Interestingly there is limited analysis of how these surveys are designed and disseminated. Martin and Boaz (2000) describe one initiative under the 'Better Government for Older People' pilot that asked a group of older people to design a consultation survey themselves, however this level of lay involvement appears to be an exception. While this review found no analysis of whether surveys designed by community members or users were of greater relevance or acceptance, it is generally accepted that surveys with strong design input from users and community members will be of greater relevance to the study population (Jordan et al. 1998).

Comment forms for particular services are a common method for soliciting feedback on services and have been identified as a form of consultation used in local government (Martin and Boaz, 2000; Lowndes et al. 2001). Increasingly computer technology is being used so comments and complaints can be made on-line. While such methods are often discussed in toolkits and guides, there is very little research analysing how they can best be used or to assess their value in contributing to the design of services.

While such methods are very common, there is concern that surveys and comment forms are invariably structured around the issues that are seen as important by professionals and service providers. While these issues may dovetail with community concerns there is certainly no guarantee that they will. The lack of evidence from the literature of community or user involvement in the design of such limited forms of consultation adds weight to this concern. Further constraints to the survey approach to consultation are that they may have low response rates and response bias, particularly in areas with relatively high levels of illiteracy and disengagement with statutory organisations.

Few studies describe or asses more interactive forms of consultation. However, Fitzpatrick et al. (2000) conducted a series of case studies of 12 area-based regeneration initiatives in the UK to assess the extent and effectiveness of youth participation. They found that more interactive forms of consultation such as focus groups and youth or community conferences were particularly useful, mainly because they allowed for,

> "Personal interaction between decision-makers and young people on the latter's territory" (Fitzpatrick et al. 2000 p.499).

Furthermore they found that focus groups could more easily include young people who were normally difficult to access. By having a one-off event, carefully facilitated by youth workers, a wider range of young peoples' views could be heard. They also identify youth conferences as a particularly valuable approach. These one-day conferences typically had 40-80 young participants, mainly drawn from schools and youth organisations, and used a workshop approach sometimes including a panel discussion with decision-makers. As identified in section 2.6., Fitzpatrick et al.'s (2000) research points to some degree of influence that such consultations can have.

However, such influence is rare and there has certainly been much criticism of consultation processes in the UK, particularly those that require quite passive interaction with communities. For example, Cornwall and Gaventa (2001) draw on their community development experience to speculate that minimal processes of consultation with limited interaction, debate and joint learning between communities and professionals do little to transform the development of initiatives and policy.

> "Processes geared at simply asking people for their views on social policy issues can serve to produce 'echoes' of dominant discourses, rather than the alternative framings of policy issues" (Cornwall and Gaventa, 2001 p.8)

Such criticism appears to be borne out within the regeneration environment of the UK. A study exploring the experiences of residents involved in urban regeneration projects carried out for the Joseph Rowntree Foundation (2000) chimes with Perrons and Skyers' (2003) study in finding that in the view of residents, consultation exercises were rarely given enough time or support to be truly effective:

> "The mechanisms for effective community involvement had been inadequate, with too little time for effective consultation. Many commented that there had been insufficient support and not enough training (a conclusion shared by many professionals)" (Anastacio et al., 2000 p.1).

Jones et al. (1998) distinguish between consultation approaches that provide participants with detailed background information and facilitated discussion and those, such as surveys and comment forms that require an immediate response. One approach that clearly falls into the more deliberative category is the use of citizen's juries. This approach has also received more attention in the literature. Developed in 1996 by the Institute for Public Policy Research (IPPR), great claims have been made about the ability of citizen's juries to enhance democracy (Coote and Lenaghan, 1997 in Pickard, 1998). Essentially they involve between 12 and 16 jurors typically selected through stratified random sampling in order to be broadly representative of their community (Pickard, 1998). The jurors deliberate over a key policy or planning question and are assisted in this by presentations from 'witnesses' who are experts in the topic being considered. The aim of the jury is to provide advice and has been recommended as a process for choosing between clearly defined policy options or for developing guidelines (Coote and Lenaghan, 1997 in Pickard, 1998).

Citizen's juries have been lauded as offering a,

> "unique combination of information, time, scrutiny, deliberation and independence" which have been said to "make this method an attractive option for addressing complex and value laden issues" (Lenaghan, 1999 p.51).

While this approach does seem to offer a valuable opportunity for members of the public to engage in specific policy and planning debates, the experience to-date of running citizen's juries raises several issues. In particular, careful attention is needed in the design and facilitation processes if the juries are to be worthwhile. For example, Lenaghan (1999) emphasises the importance of providing jurors with the kind of information needed to engage in the debate and in devising an agenda that focuses questions on specific issues rather than broader debates. For Pickard (1998) in her review of two citizen's juries, the style of facilitation is crucial and needs to be tight enough to focus the debate without stifling the free-thinking of the jurors. Furthermore, she raises questions about how representative such a small sample can be of communities divided by social, economic and cultural differences. Woodward (2000) raises concerns about the short-term nature of citizen's juries and is concerned that this encourages juries to provide immediate answers, rather than "forming part of a transformative process" (Woodward, 2000 p.240).

An important question here is whether such process can change policy and practice within authorities or service providers. In a comprehensive evaluation carried out by McIver (1998) of citizen's juries tasked to examine health issues, the majority of those involved in the juries felt that the decision-making processes within the health authorities involved had been influenced by the juries. However, this appears to be more in the form of adding weight to issues that were already on the local authorities' agendas rather than completely redirecting policy or practice (McIver, 1998).

From more international roots, participatory needs assessments and appraisals have become increasingly common as an approach to determining community views and priorities in the UK (Sellers, 1997; Cornwall et al., 2003). It is debateable whether this approach falls within the consultation category as frequently it appears to lead to more recurrent and meaningful participation. Participatory needs assessments frequently draw on a group of methods known as Participatory Learning and Action[2] (PLA). These methods have their ideological base in the work of Freire's and his concept of conscientisation, where participants are facilitated to question and reflect on the existing structures and conditions of their lives and to take action against any oppressive elements (Freire 1972). PLA methods have clearly developed out of a desire to facilitate greater critical engagement of participants and have been used to this effect in less-developed countries (Howell, P. 1998; Cornwall & Pratt, 2003).

However, while these methods ideally go beyond consultation to stimulate more critical and long-term engagement in practice, particularly in the UK, they have been used predominantly as a more participatory way for external agents to understand the issues and constraints facing specific communities. In essence,

> "PLA methods work through powerful visualizations of situations and knowledge generated in dialogue with local people, and have expanded the ability of many grassroots organisations to trigger discussion and to document and acknowledge local knowledge" (de Koning & Martin, 1996 p.11).

Many specific methods and tools have been developed around the world in order to facilitate communities in this process of critical analysis. Some examples from the participatory tool box include wealth ranking, time-lines, transect walks, seasonal calendars, body mapping; all these methods can be used to facilitate community members to discuss their own problems and issues (Kumar, 2002). In general these methods are used in groups; for some issues and contexts it is argued that it may be helpful to work in peer groups divided by age, gender or other dividing factors within the community (Welbourne, 1992).

At their best, participatory appraisals and assessments can raise the consciousness of both community members and of professionals involved in the exercises; this then has the potential to develop into very different ways of working, transforming local services and institutions so that communities can take greater control of their own development. Cornwall et al. (2003) specify the guiding principles these assessments as:

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[2] Originally know as Participatory Rural Appraisal (PRA). The change to PLA is in recognition of its application to urban as well as rural situation and the importance of action rather than just appraisal.

Principles and Practices of Participatory Well-Being Assessments

- Being guided by local people's perception of well-being and their definitions of 'need'
- Involves local people setting the agenda for action
- Emphasises multi-agency, multi-disciplinary teamwork
- Professionals spend time in the community as listeners and learners
- Uses simple visualisation methods, stresses iterative 'learning as you go'
- Achieves wide community representation through work with community institutions, opportunistic encounters in public spaces and local people's social networks
- Emphasises changing the attitudes and behaviour of professions, valuing local people's knowledge and creativity, enhancing local capacity for problem –solving and planning, building partnerships for longer-term engagement
- Uses triangulation as a means to verify findings and ensure their reliability
- Uses complementary analysis of existing secondary quantitative and qualitative data.

(Cornwall et al. 2003 p. 31)

A recent publication edited by Cornwall and Pratt (2003) presents a collection of experiences of using PLA methods, it is clear that the methods can, under certain conditions, help to trigger a process of critical engagement. The majority of these experiences come from developing countries and many positive results of using these methods are described, for example one practitioner from Gujarat, India writes,

> "The joy of witnessing communities gain confidence to carry out their own analysis and take ownership of their development process is even greater. Years later to hear from village institutions that have not only withstood the test of time but have, on their own initiative, moved beyond their initial mandates – well, it is impossible to describe that feeling in words" (Kaul Shah p.195 in Cornwall and Pratt, 2003).

There are very few published examples of similar work in the UK, however Cornwall et al.'s (2003) paper presents the experiences of a participatory well-being assessment conducted on a south London housing estate. The assessment brought together a diverse group of 30 professionals and residents from the health sector and beyond who were trained in PLA methods. Throughout the process the facilitators made a concerted effort to reach residents who would not normally get involved in community activities. They did this through talking to existing groups and networks, chance meetings in public spaces and by 'snowballing' through the social networks of those residents already involved. Cornwall et al.'s (2003) approach goes further than assessment alone as they are able to build on the results of the exercise to facilitate residents and professional to work together in a joint 'visioning and action planning' exercise. They conclude that,

> "At the end of the process, the team had gained an enormous amount. What mattered more than *what* was known, however, was *who* had found it out and *how* they had done so" (Cornwall et al. 2003 p.38).

This approach certainly appears to have reaped benefits; the researchers surveyed the members of the assessment team a year after the exercise and found that 87.5% of them, "felt that their experience had changed the way they viewed their work." And go on to say how these changes lead and deepened "a more active resident involvement" (Cornwall et al. 2003 p.39). Unfortunately, no details of the methodology of the final survey are given and throughout the paper there are only a few quotations expressing the voice of the residents and professionals involved. However, the value of the approach would certainly appear to have been appreciated by the Health Authority involved in the assessment as the approach has since been used in three further London boroughs.

Reflections on PLA methods from elsewhere do not always paint such a successful picture and have identified some common problems. During the 1990s in developing countries, PLA methods quickly found favour with development organisations and donors. This led to a rapid proliferation of PLA approaches within many project proposals and a resultant explosion of PLA training programmes. Such a rapid scale-up inevitably led to an emphasis on the methods of PLA, which became standardised so they could be easily grasped, rather than on developing a process based on a participatory philosophy that was flexible and adaptive to local contexts.

> "With any innovation there is an urge to standardize and codify, often in the name of quality. Manuals are called for and composed. Paragraphs proliferate as intelligent authors seek to cater for every condition and contingency. As texts lengthen, so too does training. The more there is on paper, the more reading and lecturing becomes the norm, and the more inhibited and inflexible participants become in the field" (Chambers, 1997 p.212-213).

The rapid scale up of PLA has led to concerns of quality as PLA exercises have been hurriedly carried out by consultants and facilitators outside the local community. This has meant that the results of the maps, diagrams, pictures and charts drawn and analysed by community members are used for reports or even journal articles, rather than as the start of a participatory process within the community; in these conditions PLA becomes like any other consultation process, arousing expectations often ending in disappointment and frustration for the communities involved. A further criticism waged at PLA has been the danger that they may perpetuate existing inequitable structures within communities as those who chose to participate in the PLA exercises are the dominant members of the society; invariably, older, better-educated men. Some PLA practitioners note the dilemmas raised by these issues:

> "When we did a PRA activity in an indigenous people's community in Surigao del Sur, it was a highly patriarchal society. The village chief had the first and last say and the people readily agreed to whatever he was saying. Should we accept this as being part of their cultural identity or should we advocate for changes? But who decides which culture is right, better or 'more progressive'?" (Clemente in Cornwall and Pratt, 2003 p.43)

As a way of overcoming these problems and bringing PLA back to its Freirian roots, the literature increasingly emphasises the importance of the attitude and behaviour of the facilitators over and above the use of the many PLA tools that have been developed (De Koning and Martin, 1996; Chambers, 1997; Kumar, 2002; Cornwall & Pratt 2003) PLA tools used in a way that does not challenge traditional relationships between outsiders and communities can be as extractive and untransformatory, both for the individuals and the organisations involved, as more conventional consultation methods.

Clearly, the kind of participatory process used by Cornwall et al. (2003) is an exception to the norm of consultation processes. However there are clear lessons on how to make consultation processes more effective. Approaches which involve community members in their design would appear to result in more locally appropriate methods, more in-depth information can be generated through focus groups and PLA activities. Time and resources are needed if these exercises are to be worthwhile and not merely successful in collecting the views of the easiest to reach. Previous sections (2.6.1 and 2.8) in the review have highlighted how consultation exercises have relatively limited impact on decision-making (for example Fitzpatrick et al, 2000; Wood, 2002; Alborz et al. 2002).

While consultation exercises clearly have a role to play in soliciting the views of the public their value in terms of increasing the level of participation of all sections of communities, particularly those most excluded, and transforming the way services are provided is limited unless they are seen as part of a longer term participatory process and there are effective mechanism for feeding views into decision-making processes. This point is emphasised by

Cook (2002) in a discussion of local authority approaches to consultation. Cook (2002) emphasises the need to "conceive of consultation as a process and not a one-off event and so acknowledge that it needs to be negotiated, sustainable and strategically managed" (Cook, 2002 p.525).

2.9.2. Representation and Recurrent Participation

In an attempt to move beyond one-off consultations, many health and development organisations have adopted a strategy of community representation within their own decision-making structures. Examples of community representation range from user representation in health programmes (Jewkes & Murcott 1998; Barnes, 1999; Robert et al. 2003; Farell, 2004), community representation in regeneration schemes (Shaw & Davidson, 2002: Purdue et al. 2000; Fitzpatrick et al. 2000; Foley & Martin 2000; Anastacio et al. 2000; Wood, 2002; Perrons & Skyers, 2003; Burton et al. 2004), lay representation with primary care structures (Alborz et al. 2002), activist representation within national government department working groups (O'Donovan, 2000) and community representation in the redesign of public spaces (McInroy, 2000). Rather than focusing specifically on representation within existing or newly established forums, some schemes have established groups of community members to take forward particular activities as well as input into broader decision-making (Marrow & Malin, 2004).

This great diversity of contexts and forums seeking user, community or activist representation has inevitably led to a variety of processes for selecting or electing representatives and structuring their participation. In the studies reviewed here, the majority of community representatives were asked to sit on boards and committees. For example, Purdue et al.'s (2000) detailed study of community leadership within 9 area-based regeneration schemes identifies a range of different roles including situations where community representatives, although required to be involved in discussions about an area regeneration scheme, had no voting rights within the committee.

It is interesting to note that surprisingly little attention is given within the literature to the specific details of the roles and responsibilities of community representatives or to the structure and content of committee meetings on which they sit. It is inferred within several studies that these meetings predominantly follow a fairly traditional format, for example Perrons and Skyers (2003) study of participation within a London NDC scheme found that a key criteria used by residents for selecting board members was that they should understand the language of bureaucracy, even to the extent of being seen as 'one of them' i.e. agency officials. It would certainly seem that community representatives are being asked to adapt to the organisational mould, rather than professionals adapting to ways of working determined by the community.

Another factor identified in several studies is how the nature of the interaction between community representatives and professionals is often geared towards the dominant professional discourse. For example in O'Donovan's (2000) study of the Irish Government's popular participative initiative known as the Women's Health Initiative, women's activists sat as representatives on the partnership structures that oversaw the initiative. Even though the representatives were very active and vocal within the partnership they were less likely to challenge professional knowledge,

> "While the NWCI (National Women's Council of Ireland) representative did resist the state's approach to conducting a public consultation and its efforts at agenda control, this resistance was generally embedded within hegemonic discourses of health" (O'Donovan, 2000 p.230).

This tendency for representatives to follow the lead of professionals – particularly in the case of health – is also identified by Hogg and Williamson (2001). They argue that,

> "Individual lay members contributions tend to cluster predominantly in support of the interests and interest holders in health care" (Hogg & Williamson, 2001 p.5).

It must be noted however, that Hogg and Williamson's paper is not primary research, but instead based on experience with user movements, NHS committees and the development of government policy and legislation. These observations should not therefore be given the weight of research findings. However, concerns that structures and processes established by dominant professionals in a traditional hierarchical format have been expressed by others,

> "The mere establishment of structures like committees effectively fails to address imbalances in power between providers and the supposedly empowered users of services." And further, that "by denying people the agency to make choices outside the frame of reference afforded by their role in these programmes and by

> overlooking the complexity of relations of power between service providers and community members, and within communities themselves, they operate with a very limited conception of participation" (Cornwall and Gaventa, 2001 p.11).

There are few examples in the literature of well-supported representatives with generally positive experiences of participating as representatives, particularly within regeneration partnerships. For example, in one of their case study regeneration areas Purdue et al. (2000) found that during the first year of the initiative, all the community representatives had been ill due to overwork and stress. These concerns appear to be borne out by the Audit Commission's (2004) study of NDC programmes which found that,

> "many residents were experiencing 'burn out' as a result of attending regular board meetings, working group discussions, project appraisal boards and a host of other activities" (Audit Commission, 2004 p.28).

In Dinham's (2005) study of residents in an NDC area in London, there appears to have been a lack of support and training provided which has fuelled feelings of inadequacy,

> "local residents perceived a lack of commitment to or opportunities for training and capacity building for genuine newcomers and many described feeling of inadequacy in formal contexts, especially board meetings." (Dinham, 2005 p.307)

Purdue et al's (2000) study did also find examples of some local leaders who gained the skills and experience to move into paid employment or take further qualifications. Unfortunately there is little analysis of what helps some community representatives to build the necessary skills and move on while others are overwhelmed, sometimes deciding to stand down as representatives.

The lack of support for community representatives and the traditional structures of meetings between agencies and representative has had a negative impact on the overall influence of representatives. However, it seems that some community representatives are able to learn 'on-the-job' and their effectiveness grows over time. For example Anastacio et al.'s (2000) case studies of four regeneration areas, two in London, one in a collapsed mining area and the other in a large metropolitan area, found a variety of experiences but in general community representatives felt they had become more effective over time and that both community representatives and officers had learnt how to make the partnership more effective. One of the key learning points appears to be providing sufficient training and support for representatives on the structures and procedures of the initiatives as well as techniques for building self esteem (Anastacio et al. 2000).

Some studies also emphasise the importance of staff learning and development alongside that of community representatives. For example, Robert et al.'s (2003) qualitative study of user representatives in mental health services in six health trusts used semi-structured interviews with staff and users as well as observation at meetings. This highlighted some of the positive impacts that users had on developing staff understanding of issues facing users. This led to changes in the information provided to patients, enhancing patient-orientation on wards, and other issues such as requiring a patient signature on care plans. One method used within the joint staff and user meetings was 'process mapping', where staff and users analysed the patients' journey through the mental health system. Reportedly staff commented on how valuable they had found this, particularly as the users involved were able to add experiences of the patients' journey which challenged their understanding of the service. Similar to Cornwall et al.'s (2003) study of a participatory well-being assessment, it appears that when professionals and users or community members work together on a joint task which allows them to analyse the context in which they are working or living, valuable knowledge and understanding - or, as Freire (1972) might term it, 'conscientisation' - is developed among representatives but also among staff and this is then capable of creating change.

Unfortunately, there are also examples where the impact of representatives on service development has been limited or even non-existent (Wood, 2002; Fitzpatrick et al. 2000; McInroy, 2000). Fitzpatrick et al.'s (2000) study of youth involvement in twelve area-based regeneration initiatives analysed the impact of youth forums. Seen by the regeneration staff as a "visible structure which could facilitate the on-going participation of young people in the regeneration process" (Fitzpatrick et al. 2000 p.501), the study found that in all but two of the initiatives, "no tangible impact on regeneration of these forums could be discerned" (Fitzpatrick et al. 2000 p.502). They identify three main causes of this lack of impact; lack of representativeness, disconnection from regeneration decision-making structures and a lack of purpose. In thinking how to encourage participation that can influence service development, consideration of all these factors is therefore crucial.

Purdue et al.'s (2000) study further highlights the lack of power of community representatives on the boards and committees in the nine area-based regeneration case studies. Representatives are quoted as saying they have found such meetings "frustrating, a struggle and a constant battle" (Purdue et al.2000 p.35) and felt a lack of power within the partnerships. Purdue et al. (2000) conclude that,

> "There is a real risk that the goodwill that existed towards partnerships such as those in this study may evaporate if local authorities are not able to change their culture and working practices away from secrecy and power" (Purdue et al. 2000 p.35).

More recent initiatives such as SureStart which aims to support children up to five years old and their families in deprived communities, have built the concept of parental involvement into their programme design. One way that this has been done is through 'parents' committees'. These forums are made up solely of parents, although often facilitated by programme staff. The only study so far to look at these committees is Marrow and Malin's (2004) study qualitative study with used focus groups with staff and parents to assess their experiences of the committees which met once a week and was supported by two staff. Over a two year period Sure Start's parent committee had grown from one to eighteen members. The experience of the parents interviewed was predominantly positive, with parents citing the ways being on the committee had built their skills and confidence and how, over time parents had been able to take on a more decision-making role and had begun organising events and managing their own budgets.

This type of committee is somewhat different from the previous examples of community representation on structures set up by local or health authorities. Here the group began with a less formal focus and initially there was no defined purpose to the group. Relating this to Fitzpatrick et al.'s (2000) study this lack of focus was cited as a constraint, however in Marrow and Malin's (2004) study this flexibility appears to have allowed the group to build their confidence and self-esteem so that eventually they could actually take on a greater decision-making role within the programme. One constraint within Marrow and Malin's (2004) study is that within their qualitative methodology they used only focus groups; this means that potentially those parents who were less confident on the committee may not have been able to voice their opinions openly in focus groups. Individual interviews might have facilitated the less confident to discuss their opinions, potentially soliciting more critical views on the parents' committee. Similarly some attempt to interview those that had dropped-out of the committee or decided not to join might have given a more detailed picture of its constraints.

A key concern when considering how to encourage community members and users to participate as 'representatives' in the forums and structures of health and regeneration schemes is how far a few individuals can actually represent the diversity of communities from which they emanate. Many authors (e.g. Jewkes & Murcott 1996; Guijt & Kaul Shah 1998; Cornwall & Gaventa 2001; Rifkin 2003) have pointed to the over-simplification of the term community, particularly in the health sector. As Guijt and Kaul Shah point out,

> "It is apparent that 'community' has often been viewed naively, or in practice dealt with, as an harmonious and internally equitable collective. Too often there has been an inadequate understanding of the internal dynamics and differences that are so crucial." (Guijt and Kaul Shah, 1998 p.1)

These internal dynamics and differences are context specific and cannot be assumed from one community to the next; however, studies from the UK, US, Australia and Canada have consistently shown the difference in levels of participation among different groups within the community. For example, Baum et al. (2000) in their study of participation in social and civic activities in Australia found a range of social and demographic variables that influence levels of participation. Of particular significance were low levels of participation among those on a low income and with low education, with poor physical and mental health, women were more likely than men to participate as were those who were married rather than divorced. Unfortunately, although they report that the area surveyed has a high number of ethnic groups for whom English is not a first language, they do not specify whether the questionnaire was translated into other languages and do not report any findings on the differences ethnicity makes in terms of low or high levels of participation.

Abelson's (2001) case study of local health care decision-making and Schulz et al.'s (1995) study both concur with Baum et al. (2000) in finding those that participate and become community representatives are invariably better off and more educated than those who do not. Schulz et al.'s (1995) survey of 915 randomly sampled people in Detroit also found that older people were significantly more likely to participate. Campbell and McLean's (2002) qualitative study in a southern English town points to some clear differences in levels of participation among Afro-Caribbean communities and white and Asian communities, the study found that while there were strong networks of family and friends among the Afro-Caribbean community they experienced a lack of unity which resulted in limited participation in civic life; this was in contrast to the white and Asian communities living in the same area.

Bias is apparent not only in individual's self-selection for participation but also from the side of statutory or voluntary organisations who actively seek out 'representatives' from the community to participate in their organisations or activities. This is increasingly true as community participation becomes a requirement in government policies. Jewkes and Murcott's (1998) qualitative study used interviews with the public and voluntary sectors to develop an ethnographic case study exploring how community representatives were chosen in four "Healthy Cities" initiatives in South East England. They found that all the community representatives involved in the initiatives were from voluntary organisations and not elected by or even chosen directly from the community. There was further selection bias in that those chosen had to know the language of community health, had to be able to communicate in English and have an office with a phone, as staff did not like using home numbers. The result was a selection process based on,

> "a shared common sense view of what 'community' was and what sort of people in what sort of combination could embody it for this purpose" (Jewkes & Murcott, 1998 p.852).

One limitation of the study was that members of the community were not interviewed to ascertain whether they felt adequately represented by the selected community members. However, even if the community had felt they were adequately represented, in this case it could be argued to have been by chance rather than by design.

Barnes' (1999) research illuminates further bias against the involvement of representatives from user groups. Through interviews with the public sector workers the study identifies a perception of user groups as self-interested and this then counts against them when agencies seek representatives of the community,

> "organising within user movements can create the conditions in which it is possible for people to act as genuine representatives of communities of identity but it can also be used to undermine the legitimacy of such representations by constructing them as expressions of self interest in the context of pressure group activity" (Barnes, 1999 p.79).

In order to address some of these concerns of representation, regeneration schemes such as New Deal for Communities have begun to use community elections to fill posts on partnership boards. Shaw and Davidson (2002) have reviewed the experience of several NDC schemes in running community elections. The key motivations for conducting elections was to enhance the legitimacy of the community representatives, increase awareness about NDC, increase direct representation of specific areas and groups within the community and establish NDC as a more legitimate regeneration partnership. Shaw and Davidson's (2002) review identifies higher voter turnout than in local government polls; for example 50% turnout in Sheffield , 43% in Bradford and 41% in Newcastle. Shaw and Davidson (2002) argue that,

> "the New Deal for Communities (NDC) regeneration initiative provides at least one example of elections where turnouts are up, young people and minority ethnic communities have a voice and people are interested and enthused by a distinctively 'local' brand of politics" (Shaw & Davidson, 2002 p.5).

Unfortunately the more recent national evaluation of NDC (CRESR, 2004) found that for the majority of NDC schemes, voter turnout was lower in NDC areas than for elections in their comparable local authority area (CRESR, 2004, p.71). However, the national evaluation respondents do highlight that elections have increased the confidence of elected board members, demonstrated accountability and attracted new board members. However they also identified that elections can be costly, time consuming, detract from the business of the board, cause division and result in few new candidates and a loss of valuable experience among board members (CRESR, 2004 p.72-73). To improve on voter turnout, the evaluation team advocate the use of more innovative voting methods, such as on-line voting, greater campaigning by candidates and for NDC to publicise the elections more effectively. While there are clearly still issues to be resolved regarding community elections, they clearly offer potential for increasing legitimacy of community representatives and broadening community interest in the work of partnerships.

Dinham's (2005) study in a London NDC, discussed in more detail in the section above, raises some further considerations to be borne in mind when using elections as a process for ensuring better representation within communities.

> "Though democratically conceived, {elections} were felt to have discriminated against newcomers to community activity who lack a 'natural constituency' of support because they have not previously been 'visible'. This has given rise to the feeling that 'ordinary' residents stand little more chance of actively participating than they did before" (Dinham, A. 2005 p.306).

It would certainly seem that as an approach to building participation, elections should be treated with some degree of caution. They are, after all, designed to generate representatives able to lead their constituents. Relying on elections as the main form of participation may, as Dinham (2005) points out, not lead to wider participation and eventual empowerment of more diverse groups within the community.

The reasons why only certain people within communities are keen to participate as representatives are explored in Wood's (2002) study of regeneration initiatives in Australia and Campbell and McLean's (2002) study. Both studies identify several factors which undermine the public's desire to become representatives. These including factors associated with attitudes of local or public organisations such as limited coordination of renewal projects, previous poor experiences including unmet expectations, feelings that professionals failed to listen and concerns over high levels of conflict at community meetings (Wood, 2002) and a lack of faith in mechanisms of representation (Campbell and McLean, 2002).

It is not wholly surprising then that there is little interest to become involved in anything more than passive consultation. While 78% of those surveyed in Martin and Boaz's (2000) study of Best Value pilot projects claimed they wanted their local council to find out what they wanted, only 21% said they wanted more say in the decisions that were taken and the majority wanted only passive consultation. Similarly, Litva et al.'s (2002) qualitative study exploring public preferences for being involved in health care rationing decisions found that while many had a strong desire to be involved through consultation, few wanted the responsibility of taking decisions. While organisational structures and processes remain in the traditional format and participation processes have limited influence on decisions, it is unsurprising that few in the community wish to participate to any greater extent than through consultation. Changes to these structures and processes are clearly needed in order to encourage participation.

2.9.3. Summary of Approaches

The approaches assessed within this review fall into two broad categories – consultation and representation. Within consultation it would appear that approaches which involve community members in the design of consultation processes are more likely to be locally appropriate. However, there are limitations to purely survey-based approaches in terms of their potential bias of respondents. More interactive and in-depth tools such as focus groups would appear to be more effective in hearing views of those who might not respond to surveys. Allowing time, support and training for these consultation exercises is clearly vital. Approaches such as citizen's juries allow for more detailed and deliberative consultation. By providing jurors with information about the issue under consultation, they are better able to give informed and considered views. The challenge here is to ensure that those who would not normally voice opinions are included in juries and that the process is facilitated effectively. However, it must be noted that much of the evidence is of negative experiences of consultation and rather than providing evidence of approaches that have been successful in hearing the views of all community members and then ensuring that these result in tangible changes to services and programmes.

One exception is Cornwall et al.'s (2003) study which demonstrates the success of an approach which allows enough time and training with attempts to include those who might normally be marginalised, along with professionals in a process of analysis leading into an action planning exercise. PLA exercises can be beneficial in this process but must remain part of this broader process and not just become a means of extracting information.

Representation has been drawn on extensively within regeneration programmes as an approach to participation. Again the lessons have emphasised adequate provision of support, information and training to community representatives to avoid 'burn-out'. There is a further lesson relating to the structures and processes that organisations establish to 'facilitate' the participation of representatives. Unfortunately the evidence suggests that more often such structures and processes are rarely adapted from the traditional form. Hence, far from being able to facilitate representatives' participation instead they require representatives to learn the ways of organisations and thus ensure the views rarely diverge from the professional perspective. Again, there are limited examples of positive experiences of well-supported representatives able to influence change and it would seem that avoiding the mistakes of the past would be the best approach for those encouraging the participation of community representatives.

All the evidence presented here highlights how representation needs to be handled very carefully. The lack of 'representativeness' of community members involved in regeneration and health partnerships needs to be acknowledged. Schemes to elect residents to partnership boards go some way to address this issue. However, attempts to ensure effective feedback and communication between 'representatives' and their communities would also appear to be important.

In light of the rather patchy evidence of successful approaches to encouraging participation, many authors (Narayan, 1995; Kelly and VanVlaenderen, 1996 and Changers, 2002) point to the need for a change in organisational culture and staff attitudes. As Chambers sums up,

> "It is no good preaching participation at the grass-roots while maintaining an authoritarian hierarchy 'above', with donor or department-driven targets, punitive management, control-oriented managers and the like" (Chambers, 2002 p.6).

2.10. Conclusions

This review of the literature has identified a wide spectrum of interpretations of participation, from merely providing information through to consultation and full control by empowered citizens. These different interpretations have their roots in three key ideological constructs of participation. Firstly, the thinking of the New Right where participation is seen as an individual's own responsibility to meet their health and social needs in a world with limited state intervention. Secondly, the increasingly dominant New Public Management approach with its emphasis on achieving health and development outcomes and targets in the most efficient, effective and sustainable way. Finally, the more radical approach, influenced by the work of Freire (1972), which sees empowering participation as a goal in itself due to its potential to transform oppressive societies.

While there is limited research evidence to support the assertions made by the New Public Management approach that participation leads to more effective, efficient and sustainable programmes, this may in part be due to the difficulties in carrying out systematic research to measure the effects of participation. However, what limited evidence there is does point to some beneficial influence on health and development programmes in all these areas. Research exploring the links between social capital, of which participation is one element, and health shows a clear correlation between low social capital and poor health. However, there is still not enough evidence to prove or refute a causal link whereby increasing participation and improving social networks leads to better health. Little work has been done to explore the link between levels of participation and empowerment, although there is some evidence to suggest that those who do get involved in community programmes do experience a greater sense of control over their own lives.

The current policy environment would certainly appear conducive to establishing empowering health and development programmes. There has been a consistently increasing emphasis on the importance of community and user participation, not only in making complaints and providing feedback on services but also becoming actively engaged in making decisions about services. The policy focus still appears to emphasise participation as a means to better achieving centrally driven programme targets and outcomes rather than seeing the benefits of empowerment as an end in itself. However, there certainly appears to be scope for those implementing programmes to build a strong element of participation within their work. This is particularly true of NDC which has at its centre a goal of community ownership. Given the importance vested in community participation, there is remarkably little guidance from health and regeneration policy makers on how this can be done in practice. This may in part be due to the lack of evidence of 'what works' in encouraging participation. This review explores successful approaches to participation in order to inform the work of the action research group. Rather than elucidating 'what works' the majority of studies identify the pitfalls of participation approaches. Only a very few programmes have used approaches that give enough time, resources, support and commitment to encouraging the participation of the most marginalised in the community and establishing processes to ensure that their participation influences and guides programme and service development.

The review has highlighted the many challenges facing organisations trying to encourage participation and, in light of this, the still limited extent of participation in UK health and regeneration schemes, dispute a conducive policy environment. A considerable gap in the evidence base is the lack of knowledge of how to encourage participation; there are few systematic analyses of what approaches can be successfully implemented in different situations or how organisations can best establish the processes and culture needed. Furthermore, the majority of studies exploring different approaches take a limited 'snap shot' view by interviewing predominantly programme staff and active community members at one point in time. None of the studies followed organisational attempts at encouraging participation over a considerable length of time to establish how the organisational actions, structures and attitudes that influence the development of participatory programmes. This review has highlighted how few studies focus on organisational culture and development in relation to ability to encourage participation. Given that several studies comment on the importance of the attitudes and behaviour of those facilitating participation, the lack of evidence of what organisational characteristics or development processes encourage such attitudes is a substantial gap.

By using an action research approach with a group of staff and resident co-researchers, this study aims not only to assess the effectiveness of different strategies to encouraging participation within a community health programme, but also to provide evidence of organisational structures, activities and attitudes that influence the extent and quality of community participation. This study goes beyond a limited 'snap shot' to provide an in-depth analysis of organisational efforts to encourage participation over an 18 month period.

Chapter 3: Methodology: Action-Research

This chapter begins with a presentation of the rationale for selecting the methodological approach used in this study – action research. As a research approach, action-research first came into use in the 1940s. Since then it has evolved not only as an approach, but also into what some have termed a 'new paradigm' (Meyer 1993; Reason & Bradbury 2001). This chapter documents these changes and the resulting wide spectrum of approaches to action research. The ontological and epistemological groundings of the approach are discussed in order to help in distinguishing the differences between action research and other research approaches. This then leads into a presentation of some of the issues identified in the action research literature concerning the nature of approach, concepts of validity and rigour and other key features such as collaboration, change and theory production. This is followed by a consideration of the unique ethical issues raised by such a collaborative approach. The final section presents a slightly different aspect of the approach used in this study – the methods used to attempt to measure participation. The complexities of trying to measure such a complex concept are discussed followed by a presentation of strategies used by others to measure participation. The following chapter, Chapter 4, presents the experience of conducting action research in practice and provides details of the data collected, process of analysis and reflections on the methodological approach.

3.1. Rationale for Choosing an Action Research Approach

The review of the literature presented in Chapter 2 identifies some of the complexities of attempting to encourage community participation. The evidence suggests that there are no straightforward solutions to encouraging participation, furthermore while the literature that systematically evaluates the effectiveness of various approaches to participation is expanding, it is still somewhat limited. These gaps in the literature reflect the gaps in knowledge facing practitioners attempting to increase participation within regeneration areas such as the one studied here.

These gaps in both research and practice directed the focus of the research and resulted in its main research question,

Which factors encourage – and conversely, discourage - the development of a participatory community health programme?

Furthermore, the extent to which practitioners were searching for an answer to this question within their own work greatly influenced the choice of action-research as an approach that could be used collaboratively with practitioners to explore the issue of participation within the realities of their work, whilst simultaneously attempting to facilitate a change process to address the central problem of a lack of community participation within the regeneration area. In summary, the main reasons for choosing action-research as the approach for this study are:

- A demand for action, rather than research alone, from residents and staff suffering from 'consultation fatigue'.
- The need for a highly flexible approach given the dynamics of community health and development work.
- The desire for, and appropriateness of, a participatory approach given that the issue under investigation is participation.
- The appropriateness of action-research as a longitudinal approach for understanding how practice can be developed and what challenges may emerge over a substantial period of time.

3.2. Action Research: Beginnings and Evolution

Action research has its roots in the work of Kurt Lewin, a Prussian psychologist who immigrated to America in 1933. Lewin is most often credited with coining the term 'action-research'. He worked with various industries and organisations with the aim of bridging the gap between theory and practice and studying changes in group dynamics. Lewin's interest lay in bringing together the experimental approach with social action into what he referred to as 'rational social management', which, as he explained:

> "proceeds in a spiral of steps each of which is composed of a circle of planning, action and fact-finding about the result of the action" (Lewin 1946 in Hart & Bond p.15).

This basic principle of a spiral of steps lives on in the majority of action-research studies along with the general concept that action-research is a process for "generating knowledge while, at the same time, attempting to change it {practice}" (Eldon and Chisholm, 1993 p.121). However, the philosophy and motivations behind action-research have developed quite dramatically over the years and this has in turn influenced the way in which action-research is carried out in practice. These changes stem from the critique of Lewin's approach given by Australian and UK educationalists such as Elliot (1981), Kemmis and McTaggart (1982) and Carr and Kemmis (1983). They have argued that the functionalist nature of Lewin's approach contradicts democratic and communitarian values. While Lewin's action-research encouraged participation, this was done to better implement the desires of the organisation's management rather than directly challenging power relations (Hart & Bond, 1995; McNiff, 1988). Lewin's approach was also criticised for being an externally initiated intervention and predominantly prescriptive in practice (McNiff, 1988).

This critique has led to a shift away from 'rational social management' to approaches which argue that action-research has the capacity to empower the disempowered and to challenge the social structures that create such power imbalances. Such approaches are typified by what has become known as 'participatory action-research' which emphasises the empowering role of the approach:

> "So, while we may be concerned to produce knowledge and action directly useful to a group, participation can also empower them at a second and deeper level to see that they are capable of constructing and using their own knowledge" (Reason & Bradbury 2001 p.10).

3.3. Typology

In order to distinguish between the different types of action-research that have evolved since Lewin's time, several authors (e.g. Holter & Schwartz-Barcott 1993; Hart & Bond 1995; Dick 1997; Badger 2000) discuss the wide spectrum of action-research approaches and emphasise the need for those involved in action-research to be clear about where their work falls on this spectrum. Holter and Schwartz (1993) offer three established approaches; the technical collaborative which is lead by the researcher, the mutual collaboration approach where the researcher and the participants identify problems collaboratively and finally, the enhancement approach which moves towards a critical dialogue to raise collective consciousness (Holter and Schwartz 1993 in Sturt 1999).

Hart and Bond (1995) go on to distinguish four main categories of action-research which move from elements of 'rational social management' towards a recognition of power and conflict within society and a need for structural change. The four types identified are, firstly, the experimental type where, similar to the technical collaborative category, problems are identified by external researchers and the process is re-educative; secondly, the organizational type with a focus on managerial-lead processes; thirdly, the professionalizing type involving practitioner reflection to improve practice on behalf of users and finally the empowering type which aims at consciousness-raising with a focus on users and practitioners leading a bottom-up process exploring issues by identifying problems and solutions (Hart & Bond 1995). This final approach is similar to Holter and Schwartz-Barcott's (1993) enhancement approach.

Boutilier et al. (1997) advocate exploring the three dimensions of power, values and goals, and resources to determine where action-research studies fit within the spectrum from technical to emancipatory. In order to understand the power dynamics beneath the areas of knowledge and decision-making, they recommend asking several questions of the study:

- Whose knowledge has legitimacy in defining the research questions?
- Who owns the project?

To explore the underlying values and goals:

- Why do the research?
- Who benefits from the research?

The resources dimension raises the questions:

- What is valued as a resource?
- Who has access to the valued resources?

(Boutilier, Mason & Rootman, 1997 p. 71)

A further point made by both Boutilier et al. (1997) and Hart and Bond (1995) is that the process of action-research is dynamic and complex and in practice a study may move between the identified types of action-research. This could either be as a planned strategy to move, for example from a study with strong technical experimental approach where the external researchers consciously increase the involvement of others in analysis and action planning. Furthermore, as Boutilier et al point out:

> "Initial enthusiasm for collectively researching and solving a real-life problem can evaporate in to a vague sense of direction in light of stakeholders' differing perspectives, interpretations, definitions and levels of commitment and resources within the project" (Boutilier, Mason & Rootman, 1997 p.72).

The need for the action-research process to be flexible is important as at different points in the study different roles and activities will suit the stage of development of the group and the context within which they are situated. However, as will be discussed below, the participatory-action research literature emphasises the values and behaviour of the initiator of the research as a key strategy for consciously moving towards the empowering end of the action-research spectrum. So, while the context is important for determining where the study sits within the action-research typology particularly in the early stages, it is the values, motivation and behaviour of those that initiate and facilitate the action research process that influence whether the study moves towards the empowering end of the spectrum.

The leaning throughout the design and implementation of this study has been towards the emancipatory end of this spectrum. However, the realities of the context of the study, i.e. as a post-graduate piece of research and externally initiated, have meant that it also has characteristics of the professionalizing type. These issues are discussed in more depth in Chapter 4, but are given here as explanation for the primary focus on issues relating to action-research at the more emancipatory end of the spectrum.

3.4. Key Characteristics of Action Research

As Reason and Bradbury point out, "there is no short answer to the question: 'What is action-research?" However, while recognising the many different approaches to action-research, several authors (e.g. Meyer, 1993: Waterman, 1998; Lathlean and le May, 2001) use Kemmis and McTaggart's (1988) definition as a starting point. They see action research as,

> "A form of collective self-reflective enquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out" (Kemmis and McTaggart 1988, p.5).

The lack of one clear definition is a reflection of the wide spectrum of action-research discussed above. In order to identify some unifying features of action-research, Hart and Bond (1995) have highlighted seven criteria which they argue are common to all types of action-research.

They suggest that action-research:

1. is educative;
2. deals with individuals as members of social groups;
3. is problem-focused, context specific and future–orientated
4. involves a change intervention;
5. aims at improvement and involvement;
6. involves a cyclical process in which research, action and evaluation are interlinked;
7. is founded on a research relationship in which those involved are participants in the change process.

(Hart & Bond, 1995 p.37-38)

Given the variety of action-research approaches and the contexts in which they take place, the emphasis on each of the features may vary from study to study. In their work on participatory action-research, Reason and Bradbury (2001) focus on five dimensions of the approach. Firstly that it should be conducted for purposes that are seen as worthwhile for the "flourishing of human persons, communities and the ecologies of which they are part" (Reason & Bradbury, 2001 p.2). Secondly, participatory action-research should enhance democratic processes by working collaboratively with the least powerful in society. Thirdly the study should aim to develop knowledge and change in practice; fourthly, they argue the need to recognise the emergent nature of participatory action-research whereby it evolves over time, remaining flexible and responsive to local dynamics. Finally Reason and Bradbury (2001) highlight the many ways of knowing recognised in participatory action-research. These are explored in section 3.5 below. Many of the characteristics identified by Reason and Bradbury (2001) seem idealistic and the extent to which they are attainable in any one study is debateable. However, by keeping these characteristics as guiding principles throughout the work, the study tended towards the emancipatory end of the action-research spectrum.

3.5. Ontological and Epistemological Groundings

Action-researchers who lean towards the emancipatory end of the spectrum have provided some useful insights into the ontological (the nature of being) and epistemological (the nature of knowing) groundings of action-research. These insights help in the appreciation of the differences between the approaches on the action-research spectrum, from experimental to emancipatory.

Kemmis and McTaggart (in Denzin and Lincoln 2000) explain the dominant ontological and epistemological perspectives as falling into four main categories; approaches which are *individualistic* as opposed to those within a *social realm* or which are *objective* as opposed to *subjective.* Each of these perspectives then result in different methodological approaches to research. The diagram below is adapted from Kemmis and McTaggart's (2000) work in an attempt to show these four dominant approaches and their resultant research traditions.

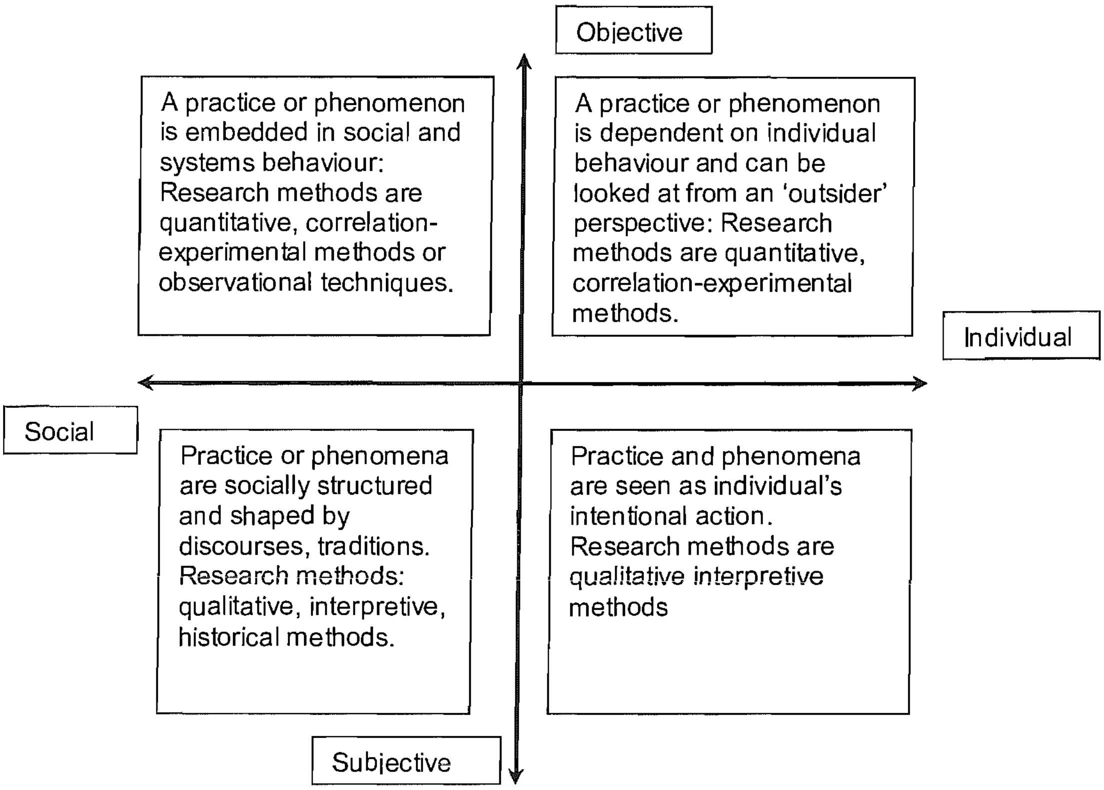


Figure 2: Ontological and Epistemological Dichotomies
Adapted from Kemmis and McTaggart in Denzin and Lincoln (2000)

Kemmis and McTaggart (2000) argue that for action-research, and particularly participatory action-research, these are false dichotomies and instead should be seen as 'dialectically related', that is as "mutually constitutive aspects of one another, both of which are necessary to achieve a more comprehensive perspective on practice" (Kemmis and McTaggart in Denzin and Lincoln, 2000 p.575). They argue for a fifth, comprehensive perspective which they believe forms the basis for participatory action-research. Under this fifth perspective the four other perspectives are related and can be seen as "mutually opposed (and often contradictory) but mutually necessary aspects of human, social and historical reality in which each aspect helps to constitute the other" (Kemmis and McTaggart in Denzin and Lincoln, 2000 p.578).

The glue which binds these four more traditional perspectives together to form the fifth perspective is reflexivity, "a dynamic process of reflection and self-reflection" (Kemmis and McTaggart in Denzin and Lincoln, 2000 p.578). They argue that this reflexivity enables those involved in the action-research process to move between the different perspectives in a dialectic way to continually deepen their understanding of their practice. This in turn influences how their practice develops and the dynamic process continues.

These arguments draw heavily on the work of Jorgen Habermas (1972; 1974; 1979); Kemmis uses Habermas' theory of communicative action expounded in works such as Communication and Evolution of Society (1979) to illuminate these processes of reflexivity. Habermas identifies four validity claims which can be asked of any communication: is this utterance comprehensible, right and morally appropriate, sincerely stated and is it accurate? (Kemmis in Reason and Bradbury, 2001 p.93). Kemmis believes these questions form the starting point of critical reflection; he then goes further to draw on Habermas' exploration of the tensions between systems and life-world perspectives. From the systems perspective the focus is on organisational structures and their functioning, whereas the life-world perspective concentrates on the dynamics of culture, social order and individual identity. Habermas sees a continual process of conflict between these two perspectives and believes that in our modern society the systems perspective with its functional rationality directed at achieving outcomes and systems goals dominates over the life-world perspective. Kemmis argues that critical reflection through action-research creates an opportunity:

> "To explore and address the interconnections and tensions between system and life-world aspects of a setting as they are lived out in practice" (Kemmis in Reason & Bradbury, 2001 p.98).

These tensions between the system and life-world aspects also help in interpreting the findings of this study and will be discussed in greater detail in Chapter 8.

Park (2001) postulates that during this process of reflection and its subsequent development of knowledge, action-research moves beyond traditional epistemological perspectives (as illustrated in diagram 1). He terms these traditional perspectives as representational knowledge of a functional subtype (assumes a detached observer) and of an interpretive sub-type (no assumptions of detachment), but then identifies two further perspectives which underpin the generation of knowledge within action-research; reflective knowledge and relational knowledge.

The reflective knowledge he describes derives from critical theory with its central tenet that argues, "meaningful human knowledge must not merely understand the world but also change it; it must be normative and oriented to action as well as descriptive or explanatory" (Park in Reason and Bradbury, 2001). The type of reflective knowledge generated through this process has at its base Habermas' theory of communicative action as described above. It also draws on Freire's concepts of 'conscientisation' (Freire, 1972) described as a "process of self-awareness-raising through collective self-inquiry and reflection" (Fals-Borda & Rahman, 1991 p.17.) which is believed to result in the transformation of their situation.

Park (2001) argues that the work of critical theorists is not enough to fully understand all the epistemological dimensions of action-research and that a further form of knowledge, relational knowledge, also underpins action-research. By drawing on feminist perspectives, Park identifies relational knowledge as residing, "in the act of relating and shows itself in words, expressions, actions and other forms of doing relationship. In relationships we know with feeling and the knowing is in the feeling" (Park in Reason & Bradbury, 2001 p.85). Park believes that this type of knowledge has an important role in strengthening communities and is evident within action-research where all parts of the action-research spiral are conducted collaboratively.

It is questionable how far a single action-research study may be able to develop fully all these types of knowledge. For example, the findings presented in chapter 4 highlight some of the constraints in establishing levels of participation that enable critical reflection of all. However, developing an understanding of these epistemological groundings helps shed light on the purpose and potential of action-research. This understanding can help to develop the process of action-research so that due attention is paid to, not only the representational knowledge generated during the study, but also to the reflective and relational dimensions of the action-research study.

3.6. The Nature of Action-Research

There is some debate within the literature on the nature of action research as either a spiral or a single cycle which in effect takes a more linear form. Again these different forms of action-research have at their root the differing epistemological emphases which determine where the approach falls within the spectrum. For example French and Bell's (1995) study as described by Badger (2000) takes a linear approach to action research where "action is suggested by hypotheses, and selected variables in the system are manipulated" (Badger, 2000 p.202). The reflection component does not dominate in such a situation and it is hard to see how many of the characteristics of action-research which set it apart from traditional research paradigms can come into play in this situation.

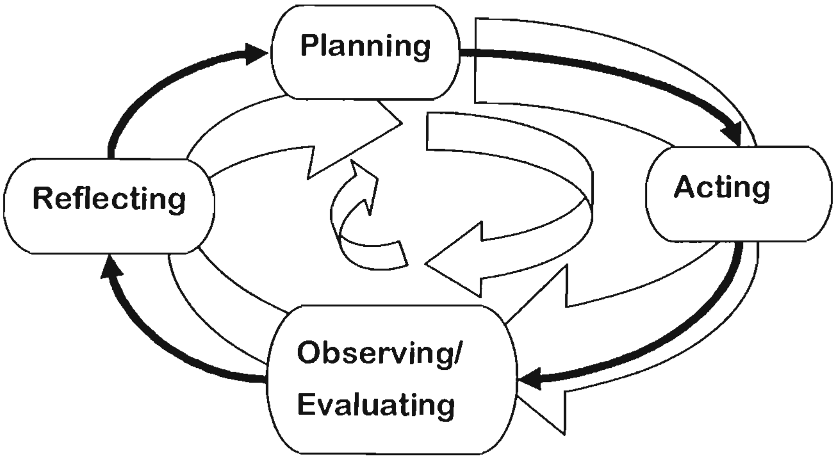


Figure 3: The Action Research Spiral

The majority of authors (e.g. Carr and Kemmis, 1986; Hart and Bond, 1995; Reason and Bradbury, 2001) refer to action-research as a spiral rather than a single cycle, illustrating that there can be several rotations of the cycle as the co-researchers try-out and reflect-on different areas of action. The components of the action-research cycle are presented in Figure 3 above. The concept of a spiral of many rotations of the action research cycle reflects not only the concept of many turns of the cycle, but also that the different elements of the cycle – planning, acting, observing/evaluating and reflecting – are closely interlinked; Hart and Bond (1995) liken this characteristic to a Russian wedding ring with the strands of gold intricately intertwined and go on to explain:

> "Our experience suggested that in each phase only one of these three strands may be dominant, although it still touches upon and interacts with the other two. This is similar to reflective practice where research, action and evaluation may be so tightly linked as to be at times indistinguishable. As a project develops over time there may be a shift so that action components dominate the research components or vice versa" (Hart & Bond, 1995 p.54-55).

The number and frequency of the rotations of the cycle will vary from study to study. However, Dick (1997) recommends that the use of many short cycles allows more chances to confirm or disconfirm emergent interpretations thus enhancing the rigour and validity of the final findings.

The observational or evaluation phase of the action-research cycle can be conducted using both quantitative and qualitative methods. This is a reflection of the ability of those involved with the action-research to emphasis different types of knowledge within their study, whether it is the relational, reflective or representational types identified by Park (2001). The use of different methods is highlighted by Hart and Bond:

> "Action research may involve sophisticated types of quantitative evaluation designed to infer the relationship between cause and effect (research intervention and outcome), or may use qualitative and/or much more informal means of evaluating processes, such as asking the participants directly for their comments on progress so far" (Hart & Bond, 1995 p.55).

There is limited discussion within the action research literature as to what type of method is appropriate in which situation and detailed guidance in this area can only be sought from more general research texts. However, discussions on the rigour and appropriateness of different evaluation methods used within action research studies would help those assessing the study to judge its validity. This point has been clearly articulated by Turnock and Gibson:

> "Whilst these authors address validity in action research, there is a vagueness in consideration of validity in the act of data collection" (Turnock and Gibson, 2001 p.472).

This issue appears to be of particular importance given the reasons for carrying out the observation/evaluation component of the action research cycle:

> "In acting the intention is practical; it is intended to bring about change. In observing the intention is theoretical; it is intended to discover the true state of affairs.... There is no temporal distinction between acting and observing, but action is monitored by observation of the task situation within which an agent finds him/herself" (Greenwood, 1994 p.14).

It would seem however, that there is a need for pragmatism here, particularly in more emancipatory forms of action-research. Using sophisticated quantitative and qualitative methodologies in situations where co-researchers are not familiar with these approaches would either involve a large investment in training or sacrifices to rigour. Kemmis and McTaggart (2000) argue that within participatory action-research it is better to collect evidence that makes sense to the group in their own context in order to progress to the next steps of planning and action without alienating group members or taking too much time. They believe that it is not only legitimate but advisable that action-research,

> "sacrifices methodological sophistication in order to generate timely evidence that can be used and further developed in a real-time process of transformation (of practices, practitioners and practice settings)" (Kemmis and McTaggart, 2000 p.591).

Reflecting on the observation data is only one part of the reflection needed in an action-research study. There is also a need to reflect on the whole process of the study including the relations within the group and the context within which the transformation is being attempted. This is most commonly addressed through the processes of individual and group reflection. Many authors (e.g. Hart & Bond 1995; Koch, Selim & Kralik 2002; Lax & Galvin 2002) recommend that the main inquirer and where possible all the co-researchers keep a reflexive diary. The prospect of all co-researchers keeping a reflexive diary seems unlikely in practice, particularly in health care settings where staff are often overloaded. Hart and Bond (1995) see the diary as a way for the outside inquirer to keeping a chronology of the research process as a means of assessing the inquirer's own performance and as a means of evaluating progress. The meetings of the co-researchers then offer the opportunity for sharing individual reflections on progress and influencing how future work is carried out.

The use of individual and group reflection in this way is key to the idea of praxis within action research which according to Koch et al (2002) is, "the process of engaging in practices that are informed by reflection is called praxis, which is achieved by critically identifying issues and collaborating to reflect politically upon practice to systematically deconstruct it" (Koch et al., 2002 p.110-111).

Carr and Kemmis (1983) make the distinction between "practice as habitual or customary, on the one hand, and the informed, committed action of praxis, on the other" (Carr and Kemmis, 1983 p.165). Their explanation of praxis has at its core the concept of 'theorising practice' where practice is set in a 'critical framework of understanding which can inform practice and articulate the commitments which vitalise it." Furthermore, praxis involves a recognition of the practitioner's ability to make judgements about a "wise and prudent action" (Carr and Kemmis, 1983 p.165).

3.7. Validity and Rigour

As a process, participatory action research should conform to the concepts validity or credibility that underpin qualitative research (Waterman, 1998). However, concepts of validity and particularly reliability have their roots in the positivist paradigm and there is much divergence within the qualitative literature on their relevance within the naturalistic paradigm (Denzin and Lincoln, 1998; Patton, 2002). It would appear that ensuring the reliability, as understood in positivist terms as the ability to reproduce the same results, has great limitations within qualitative research where the subjectivity of the researcher and the influence of context and structure are acknowledged. However, Mays and Pope (1995) argue that while reliability is a problematic concept within qualitative research, there are still ways to maximise its potential. Primarily they argue that the researcher must, "maintain meticulous records of interviews and observations and by documenting the process of analysis in detail" (Mays and Pope 1995 p.110). Furthermore this can be enhanced by asking others to assess the coding of transcripts and comparing in order to identify discrepancies.

Within action research the concept of reliability is rarely discussed, instead the focus is on the validity of study, and for both qualitative and action research this seems to pose fewer epistemological and ontological challenges. A key concept for increasing validity in both qualitative research and action research is triangulation. This concept refers to the comparison of a range of different data collected from different sources using a variety of methods. As Denzin explains:

> "By combining multiple observers, theories, methods and data sources" researchers can hope to "overcome the intrinsic bias that come from single-methods, single-observer and single-theory studies" (Denzin, 1989 p.307).

It can be argued that action research has an inherent advantage here as it relies on multiple observers through the process of evaluation and different perspectives throughout the process of analysis and reflection and it is very probable that a number of different methods and data sources will be used within the observation phases. All these factors will help to increase the validity of the findings of each action research cycle.

Feeding back findings to research participants is another technique identified by qualitative researchers as enhancing validity (Patton, 2002). Again, here action research seems to be at an advantage as the co-researchers are continually able to discuss and check the validity of the findings. Where the group includes an 'outsider' researcher conducting some degree of the analysis independently form the rest of the group, a more structured process for this feedback would further help to enhance validity.

However, several authors claim that action-research includes processes that can further strengthen validity. Waterman (1998) has argued that "the qualitative perspectives on validity do not portray adequately all that makes action-research valid" (Waterman, 1998, p.101) and identifies three further elements to assessing the validity of action-research, dialectical validity, critical validity and reflexive validity. Dialectic validity refers to the increased validity created by working through the action-research cycles as a group and in the process, moving between theory, research and practice and dealing with conflicts and tensions that this process will inevitably produce. Critical validity refers to the extra validity gained through the emancipatory ideals and philosophy which underpin action-research and the aim to improve the situation of those involved in the action-research. Reflexive validity, Waterman believes can be achieved through action-research as 'biases or prejudices are brought to the fore and analysed in order to understand researchers' influences on the project" (Waterman, 1998 p.104).

Dick (1997) identifies six characteristics of action-research which he argues can achieve high levels of rigour and validity:

1. Action-research can make use of its cycles to try to disconfirm any emerging interpretations
2. At each turn of the cycle the methods used can be critiqued and refined
3. Data collection and its interpretation are included in each cycle so they can be continually tested in later cycles
4. Divergent data can be specifically sought out
5. Literature can be used as a source of possible disconfirmation
6. Changes are planned in light of previous cycles of data collection and interpretation, the change offers a further opportunity for disconfirmation.

With reference to the emancipatory end of the action-research spectrum, McTaggart (1997) describes these strands of validation as being,

> "typically, an extended process of iteration between the data and the literature which informs the study. That is, validation is an explicit process of dialogue, it is not achieved by adherence to a fixed procedure. Validation in participatory action research can only be achieved if there are appropriate communicative structures in place throughout the research and action that allow participants to continue to associate and identify with the work of the collective project of change" (McTaggart, 1997 p.13).

McNiff (1988) takes this a stage further and stipulates that discussions of the validity of action research should not focus on the methodology but instead, "the validity of the approach lies in the skills of the enquirer; it is more personal and interpersonal" (McNiff, 1988 p.7). However, for those outside the study, using the skills of the enquirer as the primary criteria on which to judge the validity of the findings is clearly problematic. For example, how can these skills be recorded and accurately portrayed in final reports or research articles, particularly when these are often written by the enquirer themselves? Evidence of the enquirer's continual reflection on their skills within that process is clearly valuable in this respect.

The development of research strategies to disconfirm and continually test any emergent interpretations, coupled with continual critical reflection and documentation of enquirer/group relations help to strengthen the validity of action-research. However, it is important that such strategies are systematically planned into the action-research process to ensure that they really do happen. Reporting on how far such validity measures have been implemented and how successful they were is key in assessing action-research studies. Unfortunately many published studies do not describe or reflect on these processes making it hard to assess claims of validity.

3.8. Action-Research as a Collaborative Process

Grounded deep within the philosophical and epistemological underpinnings of action research, particularly participatory action research, is the idea that research is done *by* people rather than *on* people (Kemmis in Reason & Bradbury 2001). In practice, this results in the establishment of a group of co-researchers who have ownership of the study. While the term 'co-researcher' indicates an equal relationship between all those involved, it is clear from the literature that this is rarely the case and conscious effort must be made to try to overcome power differentials among the group. McTaggart (1997) argues that these tensions are often interlinked to a lack of clear understanding about what participation really means:

> "Participatory action research is in principle a group activity. But in situations where people with different power, status, influence and facility with language come together to work on a thematic concern, the idea of participation becomes problematic. A disturbing confusion about the nature of participatory action research arises because of the corruption of the meaning of the 'participation'" (McTaggart, 1997 p.28).

Particularly problematic is the relationship of the initiator of the research to the other members of the co-research group. Lathlean and le May (2001) link the problematic nature of this relationship with the fundamental goal of action research to create change:

> "Since the design inherently seeks to facilitate change there is the possibility of tension arising between the initiator of change and those involved in the process of change if they are not one and the same. While essentially empowering, this process may be seen as coercive and divisive if the proposed change is imposed or pushed forward without necessary preparation rather than being negotiated and agreed" (Lathlean and le May, 2001 p.505).

In order to be aware of and respond to these tensions, Reason believes the initiator should ask:

> "Who is the research really for? And is there a genuine possibility for co-operative endeavour? If there is an inquiry task around which a group of people can genuinely join to explore, than any problems of initiation, ownership and power can be resolved through authentic negotiation and confrontation. But if there is no such possibility of a shared inquiry task, then, the group will have been set up on a phoney basis" (Reason, 1988 p20-21).

Lathlean and le May (2001) recommend those involved in the study to be clear about the nature of their roles and agree on a strategy for researcher participation in order to secure "ownership of the change by the participants, as well as sustainability following the end of the project and the withdrawal of the researcher" (Lathlean and le May, 2001 p.506).

Much of the literature classifies the researcher as having either an 'insider' or an 'outsider' role. Titchen and Binnie (1993) define the insider as combining 'the roles of actor, change agent and researcher' and the outsider as having no authority for change but who can provide a diagnostic function and feed-back observations (Titchen and Binnie, 1993 p.859).

Even when the role of the researcher/initiator are negotiated and agreed, imbalances among the group of co-researchers are still inevitable, particularly when the outsider is a formidable individual and when the group includes people at different levels of seniority in an organisation or from different education, class, wealth, race and gender groups, as Rahman explains:

> "It is not easy to establish a truly subject-subject relation at the very outset with people who are traditionally victims of a dominating structure – the inertia of traditional attitudes and images of self and of others may keep the people implicitly subordinate in a research (as well as a decision-making) process in which formidable outside researcher/activists are present" (Rahman in Fals-Borda & Rahman, 1991 p.13).

Meyer (1993) identifies with the unequal power relationship between academics and practitioners, "The researcher is also powerful by being seen as an academic expert belonging to another world with which not all participants will be familiar" (Meyer, 1993 p.1070).

Recognising these power differentials within the group appears to be the first step in overcoming them, along with a clear vision of the kind of participatory relationship that is desired among the group. McTaggart articulates his interpretation of participation:

> "Authentic participation in research means sharing in the way research is conceptualised, practiced and brought to bear on the life-world. It means

> ownership, that is, responsible agency in the production of knowledge and improvement of practice" (McTaggart, 1997 p.28).

Some of the reports of action research emphasise the attitudes and behaviour of researchers to encourage participation. Trust and respect were key for Maria Salazar (in Fals-Borda & Rahman, 1991) when working with young labourers in Bogotá, Colombia; respect for local knowledge is a fundamental underpinning of action research and is a recurring theme within reported studies (Koch, Selim & Kralik, 2002). Stringer (1996) emphasises the need to accept and be sensitive to others views, maintain harmony within the group by resolving conflicts and encouraging co-operative relationships. Chambers (1995) discusses how dominant outsiders, whom he refers to as 'uppers' can change their behaviour:

> "From planning, issuing orders, transferring technology and supervising, they shift to convening, facilitating, searching for what people need and supporting. From being teachers they become facilitators of learning. They seek out the poorer and weaker, bring them together, and enable them to conduct their own appraisal and analysis, and take their own action. The dominant uppers 'hand over the stick', sit down, listen and themselves learn" (Chambers, 1995 p. 34 in Reason & Bradbury, 2001 p.73).

This continual reflection on attitudes and behaviour not only by the outsider researcher, but by all those involved in the action research process can, it is argued, lead to more authentic participation of all co-researchers. Furthermore, such reflection and adaptation of behaviour potentially presents a real challenge to underlying power relations among the group.

3.9. Institutional Change

The prospect of changing practices and approaches of the members of the co-research group is challenging in itself. However, action research by its very nature, goes one step further and attempts to challenge the institutions and societies that surround the co-researchers:

> "Participatory action research is concerned simultaneously with changing individuals, on the one hand and, on the other, the culture of the groups, institutions, and societies to which they belong" (McTaggart 1997 p.31).

This drive for change of individual, group and organisational culture into a more emancipatory state inevitably leads to conflict as old ways of working are challenged.

> "The group must ultimately engage in an ideology critique to ensure its work is not misdirected and its understandings not distorted by deference to illegitimate authority" (McTaggart, 1997 p.33).

Several action research studies from the nursing literature highlight the conflict they have encountered due to dominant organisational cultures which do not fit well with the participatory framework. For example, Sturt (1999) describes the tensions she experienced when the practice nurses involved in the action research were reluctant to challenge existing organisational structures and this ultimately led to her withdrawal from the study. Clearly, when such hierarchical ways of working are deeply entrenched the possibility that an action research study can make rapid changes is unlikely and may put undue pressure on the co-research team. Cornwall and Gaventa (2001) stress the importance of keeping organisational and institutional change as a long-term goal and note that often a high-level 'participation champion' within the organisation can support this process.

3.10. Action-Research and Theory Production

One area that has received limited coverage within the main action research texts is the potential for action-research to generate theory. Within much of the available material the discussion of theory generation stops with a recognition that part of the role an action research study is to generate knowledge to inform practice,

> "Research carries with it some important connotations: intensive study of a situation and production of knowledge in some form or another, including important ideas like informed practice" (McTaggart, 1997 p.27).

McTaggart (1997) argues this is done through collecting "compelling evidence that could convince them that their previous practices, ideas and assumptions were wrong or wrongheaded." The collection of such evidence then allows the action researchers to justify their "work to others because they can show how the evidence they have gathered and the critical reflection they have done have helped them to create a developed, tested and critically examined rationale for what they are doing" (McTaggart, 1997 p.39).

While this process is clearly of value to those immediately involved in the local situation where the action research is taking place, there is less clarity as to how those external to the situation can interpret the findings of the action research study. Someone external to the particular action research situation would be wise to question whether the findings are applicable and whether similar change processes would work in their own situation. When the emphasis is on improving local action alone, clearly these questions are somewhat irrelevant to the action researchers immersed in their local situation. However, even the term 'action research' infers that to only concentrate on the 'action' element is not sufficient and that 'research' is also required.

Carr and Kemmis' (1983) work, with its groundings in Habermass' discussions of praxis, emphasises that the action within action research is "informed by a practical theory.... which may, in its turn, inform and transform the theory which informed it" (Carr and Kemmis, 1983 p.165). Hence the processes of following the stages in the action-research cycle allows the evolution of theory, as knowledge is continually generated within the group.

Lathlean and le May (2001) address this concern by stating that, "action research that is not theory generating can not claim to be research, but is some other form of action based inquiry" (Lathlean and le May, 2001 p.503). So, what research should an action research project do in order to develop theory? Titchen and Binnie (1993) argue that action researchers such as Kemmis and McTaggart do not allow for sufficient observational studies within their action research spirals in order to develop theory. They draw on the work of Brown and McIntyre (1981) who state that "theory generation, through action research, should be based, not only on prior observational research, but also on exploratory observational research, running continuously alongside the action and the study of its outcomes" (Brown and McIntyre in Titchen and Binnie, 1994 p.6). In light of this they argue the need for a reconnaissance phase at the beginning of an action-research study. Such a phase is defined by Street (1995) as "a specific fact finding process that involves a systematic exploration of a specific situation in order to provide an informed basis for development of the first action plan" (Street 1995 in Koch et al. 2002 p.11).

In their own work, Titchen and Binnie (1994) began their action research process with a case-study of the ward in which their study would be based. This case study, along with the relevant literature and personal experience, was conducted in order to, "generate a theorised account of the situation one is trying to change and to develop tentative principles for action" (Titchen & Binnie, 1994 p.9).They were then able to continually test these principles and develop new principles throughout the spiral of action research. The box below provides an adaptation of the criteria they feel are valuable in designing a study that is capable of generating theory.

An Adaptation of Titchen and Binnie's Action Research Criteria for Generating Theory

1. An initial observational study is conducted to generate a theorised account
2. Tentative explanatory principles for action are devised from the data, relevant social science theory, empirical work and personal knowledge of change.
3. Action hypotheses are generated to test and refine the principles in the field
4. Action is the operationalisation of the principles and is, therefore, theoretically informed.
5. Questions are developed to the determine the effectiveness of the action in achieving its goals
6. Theoretical sampling of people and situations is carried out
7. Hypotheses are falsified or refined for further testing until clear explanatory principles can be generated
8. At the same time, observational studies are conducted, asking questions of actor's perspectives of action and ability to meet goals
9. Theorise and generalise findings by:
    a. Providing readers with a rich description, interpretation and explanation of the situation. Readers can then judge how relevant the situation is to their own and hence, how applicable the findings.
    b. Drawing on substantive social science theory, existing empirical data and personal knowledge
    c. Establishing abstractions and generalisations across individual cases.
10. Findings and theorisations are laid open to public scrutiny

(Adapted from Titchen & Binnie, 1994 p.9)

Titchen and Binnie's (1994) criteria are useful in providing clarity as to the steps that an action research study should undertake in order to legitimately claim to generate theory. It is important to re-emphasise the point they make under 9a, that such action research generated theory does not intend to be generalised indiscriminately across populations and situation, but as Meyer (1993) points out is closer to concepts of transferability used within naturalistic inquiries,

> "This type of research generates principles and guides for dealing with different situations. The reader of in-depth case studies is left to decide their relevance to themselves in their own situation" (Meyer, 1993 p.1068).

Transferability or 'external validity' as it might be understood within a positivist paradigm, refers to the possibility and limitations of applying the study's findings beyond the context in which the study was done (Malterud, 2001).

It is interesting to consider how the need for theory generalisation and the observational studies and literature reviews it involves, sit with the goals of participatory action-research to facilitate emancipation. There is a little discussion as to *who* should carry out such observational studies and *who* should delve into relevant social science theories. Such work is time consuming and lends itself to someone with an academic background; hence it would appear that the most straightforward way of meeting these criteria is if they are carried out by an outsider researcher. Potentially, this addition to the role of the outsider researcher could deepen the insider/outsider gulf by reinforcing the perception of the outsider as the 'expert' with in-depth knowledge of the nature of the problems found in the insider's context as well as technical research expertise. Continual observation throughout the action research cycle by only some members may further undermine trust among the co-researcher group. Caution is needed and continual feedback and discussion of this kind of information would be necessary to overcome any further distortions of power within the group.

Lathlean and le May (2001) note the legitimacy of both the insider and outsider roles and recognise that each study will emphasise different action research characteristics, some favouring theory generation and some favouring emancipation of co-researchers. This tension is discussed by Badger (2000) who argues that,

> “Practitioners may thus see action research as a way of introducing change, valuing only action, and regarding theory building and methodological considerations as irritation and delay” (Badger, 2000 p.205).

However, it is unclear whether it is possible to pursue the two goals of emancipation and theory generation in one study or whether the goals are in fact contradictory. Lewis (2001) in her work with Highlander adult education in Tennessee, notes how, “when people learned how to do their own research, they began to recognize that experts are not the objective, unbiased, disinterested purveyors of truth” (Lewis in Reason & Bradbury, 2001 p.361). This process proved to be liberating for many involved in the Highlander project and raises the question of whether training and support of co-researchers to carry out observational studies and to review relevant literature themselves could be valuable not only in meeting the needs of theory generation, but also in supporting the emancipatory aims of action research.

3.11. Ethical Considerations

Several authors have highlighted how action research faces specific ethical considerations over and above those found in other qualitative or quantitative studies (e.g. Meyer, 1993; Hart and Bond, 1995; Lathlean in De Raeve, 1996; Sturt, 1999; Badger, 2000; Meyer, 2000). These concems cover several areas: the level of transparency of outsiders in negotiating to initiate an action research study, the ability of potential participants/co-researchers to give informed consent to participate, problems of confidentiality and issues of ownership particularly where the study is for an academic qualification. All these concerns spring from the very nature of action research as a collaborative, evolutionary process.

Lathlean (in De Raeve 1996) goes on to argue that ethical concerns can appear from the very initial discussions between those wishing to initiate an action research study and those in the practice environment who are in a position to decide whether the study proceeds or not. In situations where action-research is not a well known and accepted approach, the initiator may not be entirely honest about what is involved in the study in order to convince others of its merit; in particular, the level of commitment in terms of time and energy required by co-researchers/participants.

Meyer raises concerns as to “the extent to which participants can truly give informed consent, when the nature of the proposed change is unknown and determined by an emerging reality.... The proposals for change come from within the group of participants and as such is a step into the unknown for individual players” (Meyer, 1993 p.1069). Several studies discuss the tensions that arise as participants find themselves involved in a study that challenges their practices and often, core beliefs and furthermore, challenges wider institutional culture potentially placing participants in positions of conflict with others in the organisation (Sturt, 1999; Lax & Galvin, 2002; Williamson & Prosser, 2002).

As action research gives much attention to the developing relationship within the action research team and to the actions of participants, these must be presented in some way in the final report of the study. Maintaining confidentiality and anonymity is clearly challenging, “action research is often written as case studies and as such confidentiality and anonymity are potential problems to be explored with participants” (Meyer, 1993 p.1071). Lathlean (in De Raeve 1996) recommends using concepts and theorising instead of using specific examples that might indicate a participant’s identity. Where possible, she recommends obtaining the permission of participants to publish findings, clarifying whether they are prepared to be identified and sharing copies of reports so they can challenge interpretations or ask for sensitive material to be removed. Meyer (2000) recommends that the co-researchers and any external researchers agree on an ‘ethical code of practice’,

> “Conflicts may arise in the course of the research: outside researchers working with practitioners must obtain their trust and agree rules on the control of data and their use and on how potential conflict will be resolved within the project” (Meyer, 2000 p.320).

Undertaking an action research study as part of an academic qualification raises further ethical concerns as the student will inevitably need to focus on producing a piece of work that is academically acceptable; this may shift the emphasis of the study away from action towards research. Hart and Bond (1995) express concerns that this may create a manipulative situation where co-researchers/participants are unable to pursue their preferred goals of improved action as the process becomes dominated by the need to fulfil academic requirements. Lathlean (in De Raeve 1996) also identifies the contradictions that may face those using action research to work towards an academic qualification as the research student, “must be able to present a thesis or dissertation that is clearly their own work, yet the extent to which it is based on a joint effort has ethically to be recognised" (Lathlean & le May, 2001 p.40).

3.12. Measuring Participation

During the design phase of the research several of the programme and partner organisation staff were keen that the study should attempt to measure changes in participation levels within the programme. At first this seemed a complex and possibly unhelpful focus for the study; a quick glance at the literature was enough to show that the concept of measuring participation raises a great number of challenging questions including the viability and value of attempting to quantify something as complex and multifaceted as participation. However, after some reflection and further discussions with the programme coordinator we agreed that as there was such interest in this area it could be useful to attempt to assess the extent and levels of participation at different points within the programme. In order to do this, I explored the literature on measuring participation to see how others had attempted to do this.

The body of literature on measuring participation is fairly minimal, much of what does exist in this area comes from experiences in developing countries where participation has become an increasingly standard component of development programmes (Estrella et al., 2000). Some of these approaches have been used in the Europe (Rifkin and Bjaras, 1991) and Canada (Laverack and Labonte, 2001) and would seem to be valuable in the so-called developed, as well as developing countries. Two key questions within the debate on measuring participation are *what* should be measured and *how* should it be measured. Several authors argue that any evaluation of participation levels and quality should itself be participatory (Blauert and Qunintanar in Estrella et al. 2000), so another question to add is *who* should measure changes in participation.

Rifkin et al. (1988) discuss the problematic nature of evaluating health outcomes in a linear fashion to determine direct causal relationships. The inadequacies of such traditional evaluation methods are particularly true when measuring participation.

> "The weaknesses of assessing economic development and health improvements in terms of linear causal relationships and /or through tightly controlled studies are magnified when trying to assess community participation. These efforts are complicated not only by lack of a clear definition of the terminology but also by the specific cultural, historical, social, economic and political environments in which they take place" (Rifkin et al. 1988 p.932).

In light of this they recommend looking at relative measures that assess the process of participation within programme development rather than final static outcomes. Laverack and Labonte's (2000) conceptualisation of participation as a step towards potential empowerment, adds weight to the idea of measuring participation as a dynamic process rather than a final outcome. Burns and Taylor (2000) draw on experiences from social audits to develop their participation audit tools. They identify the characteristics of social audit as a process that draws on many perspectives, reflects local circumstances, encourages enquiry and learning, is peer driven rather than top-down and can be qualitative rather than just quantitative (Burns and Taylor, 2000).

Rifkin et al. (1988) have, after assessing over 100 case studies, developed 6 factors which influence participation: needs assessment, leadership, organisation, resource mobilisation, management and a focus on the poor. These factors then form the basis of a diagram where each of the arms provides a scale on which to measure the extent of participation within each factor. A ranking exercise can then be conducted with different groups of stakeholders in order to encapsulate differing perspectives.

The design developed by Rifkin, Muller & Bichman's (1988) and the characteristics of social audit identified by Burns and Taylor (2000) formed the basis of an exercise for measuring participation. This experience of doing this in practice and a reflection of its value is given in the following Chapter.

Summary

This review of the literature has highlighted the broad spectrum of approaches within the action-research typology. The essential characteristics of knowledge generation not only grounded in the realities of practice but also as an emergent process striving to change practice make it an ideal approach to explore and attempt to encourage participation within community health programmes. While action-research has much to offer situations such as those found in the regeneration area, the potential of participatory action-research to empower those who get involved with the study make it an attractive approach for exploring issues of community participation within a health programme. The extent to which these ideal characteristics can be realised in practice is debateable and reflections on the experience of using the approach are given in the following chapter, Chapter 4.

Chapter 4: Findings I: Action Research in Action

The previous chapter highlighted the philosophical, methodological and practical issues surrounding the action research approach. This chapter presents the experiences of implementing this approach in practice. This includes details of the design of the study, the recruitment process, the phases of the study, the methods of data collection and analysis, the strategy used for measuring participation and the steps taken to increase validity and rigour within the study. In light of the experiences of the study, reflections on key issues within the action research approach are presented exploring where the study sits on the spectrum of action research approaches, my role and the sustainability of the group and finally some ethical considerations.

4.1. The Design of the Study

The original terms of reference for this research were developed collaboratively by New Deal for Communities (NDC), the School of Nursing and Midwifery and the local Primary Care Trust but were sufficiently broad in their remit to offer scope for the development of both the central topic and methodological approach. This provided an opportunity to shape the project to address an issue not only of interest to me, but also of central importance to New Deal for Communities' health programme and the residents of regeneration area.

The first four months of the project were spent consulting with staff from NDC and its partners and community members involved with the health programmes. Figure 5 below documents the meetings held during this design period. During these consultations I asked about the key issues facing the health programmes in the regeneration area and how a research project could be of use in addressing these issues. Out of this process and some exploration of the literature, I began to develop options for the topic and methodology of research. These options were presented to the Community Health Working Group where the staff and residents voted for the option they felt would be the most beneficial to the programme. They chose participation as the central issue to be addressed and recommended an approach that would facilitate immediate action as well as research. The central question for this action-research study is therefore:

Which factors encourage – and conversely, discourage - the development of a participatory community health programme?

After further development, I presented the aim, objectives and methodology for this option to the NDC Board. The Board approved the study and requested that I keep them informed of progress and findings (hence Objective 5). The diagram below shows the process followed in designing the study.

Figure 4: Finding the Focus for the Study

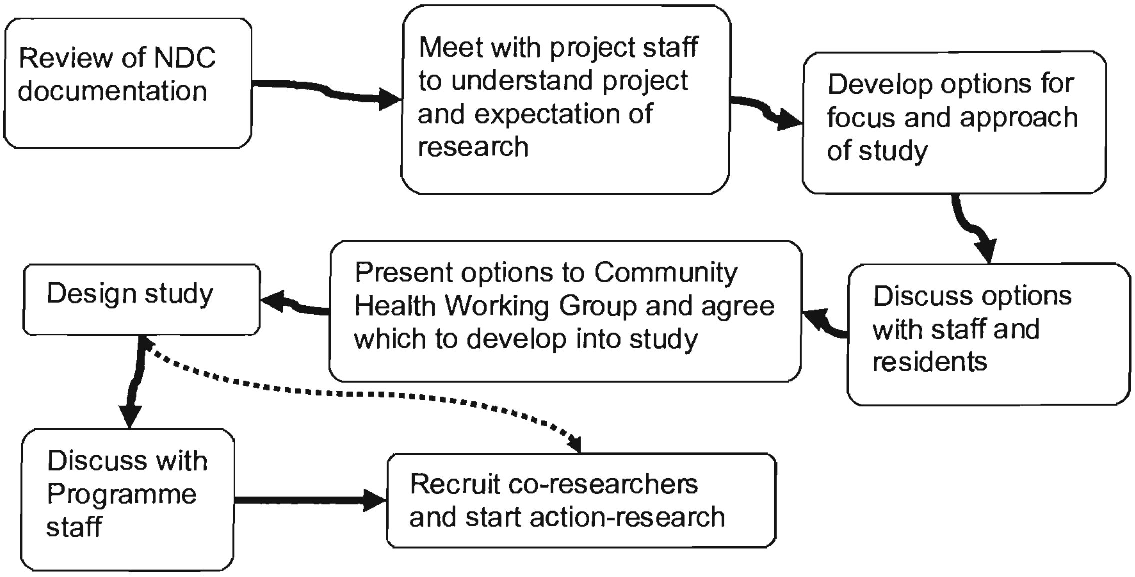


Figure 5: Organisations and Residents Consulted during the Design Process

Organisation/Resident	*Role*
3 x Residents	All Health Working Group members
NDC	Health Lead Officer
NDC	Programme Co-ordinator
NDC	Community Development Worker
NDC	Crime Lead Officer
NDC	Environment Lead Officer
NDC	Long-term Health Needs and Access Project Officer
PCT	Health Visitor
PCT	Mainstreaming Sure Start Manager
City Council	Leisure Development Team Leader
Sure Start/City Council	Evaluations Officer

While this process may appear somewhat longwinded, in retrospect I believe it was crucial not only in increasing the possibility that the research would be of value to the health and development work in regeneration area, but also in building ownership of the project within the health team and NDC as a whole. For an action-research study, building a strong sense of ownership among the organisation or community involved is vital for the project to function with the level of commitment required from participants in the action-research group and from the organisation of which they are part, not only in terms of time, but also in willingness to change practice (Reason and Bradbury, 2001).

The discussions over the different options also helped to clarify the reasons for not focussing on other issues or using different research approaches. For example, there was a desire among the primary care trust and some of the NDC staff to conduct an evaluation of the health programmes. Further discussions soon clarified that many of the health programmes had only recently started their work in the area and it would be too early to evaluate any changes these programmes may have influenced. The transparency of these discussions has resulted in a much stronger buy-in to the final design of the study which has helped in the relative smooth running of its implementation.

The final component of the design stage was to negotiate which health project would host the research. Given the choice of action-research as the methodological approach, this was an important decision and to a large extent was dependent on the commitment of the programme co-ordinator and programme staff. After making the level of commitment explicit to the coordinators of all the health programmes, it was the programme for family support that showed the most enthusiasm and commitment to the action research study concept. This was then approved by the sub-group for the programme.

4.1.1. Aim and Objectives

During this design process an initial aim and set of objectives were developed for the study. These were then discussed by the action research group in the early sessions of the study. This resulted in some adaptations until the following aim and objectives were agreed on to guide the study:

Aim:

To identify factors which enable and constraints which restrict community participation within a health programme in a regeneration area.

Objectives:

1. **To understand the meanings and motivations for participation from the perspectives of agency staff and community members.**

2. **To assess the effectiveness of various action strategies in improving the extent and quality of participation from the perspectives of community members and programme staff.**

3. **To explore the value and effectiveness of techniques to measure participation.**

4. **To analyse the experiences of a team of co-researchers in their efforts to encourage participation.**

5. **To share the experiences, lessons learnt and findings from the study with others in the regeneration and health programmes.**

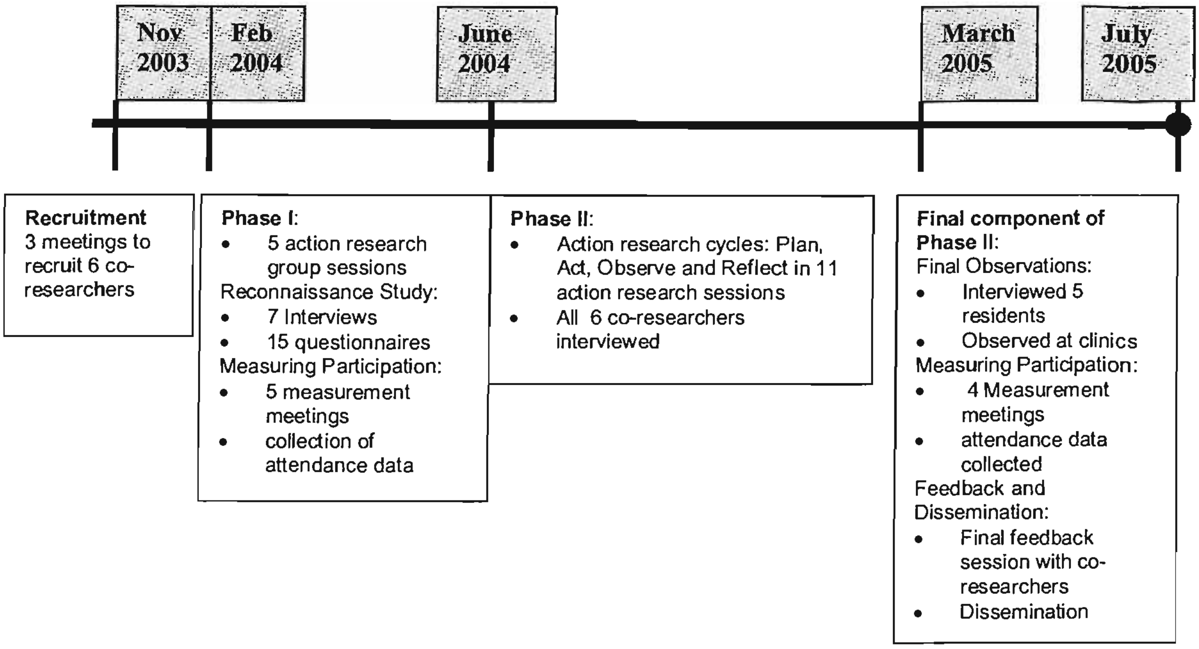
4.2. Recruitment and Details of Co-Researchers

At the heart of the study was a core group of seven co-researchers, all of whom volunteered to join the study. These include three locality family workers, a health visitor, a resident, the programme co-ordinator and myself - the facilitator/researcher. Their recruitment took place in November 2003 when I attended health visitor, midwifery and locality family worker team meetings in order to introduce the study, explain the commitment involved and invite the staff to join the group, this was done by oral presentation and by giving out the information sheets and consent form (see appendix 3). At these initial recruitment meetings there were 8 locality family workers, 3 of which agreed to join the study and 3 health visitors or which 1 agreed to join. Of the 5 midwives who attended the recruitment session none felt they could join the action research group due to an extensive and unpredictable workload, however they requested to be kept informed about the study as it progressed and were happy to get involved in any related events that could be fitted in to their schedules.

Recruitment meetings were also held for residents involved with the regeneration programme at various working group meetings. Of a potential 6 residents, one agreed to join the group due to her personal interest in services for families in the area – she was looking after a toddler grand-daughter – and her experience as a community activist. The programme coordinator agreed to join the study early in the design process after showing enthusiasm that the study should be situated within her programme. While the group included one non-staff resident co-researcher, two of the staff co-researchers were also residents of the area, one had been a resident when her children were growing up and one lived in a similar area near by. Only I and the health visitor co-researcher had never lived in the area or similar.

In order to maintain anonymity, only limited details of the backgrounds of the co-researchers will be described here. However, in order to help the reader consider the transferability of the findings of this study to their own context, it may be helpful to know that the co-researchers were all women, they were aged between 30 and 60 years old, of various educational backgrounds with qualifications ranging from secondary school level to university degrees, they were all white and all except myself had at least one child.

4.3. Time Line of the Study



Recruitment
3 meetings to recruit 6 co-researchers

Phase I:
- 5 action research group sessions

Reconnaissance Study:
- 7 Interviews
- 15 questionnaires

Measuring Participation:
- 5 measurement meetings
- collection of attendance data

Phase II:
- Action research cycles: Plan, Act, Observe and Reflect in 11 action research sessions
- All 6 co-researchers interviewed

Final component of Phase II:
Final Observations:
- Interviewed 5 residents
- Observed at clinics

Measuring Participation:
- 4 Measurement meetings
- attendance data collected

Feedback and Dissemination:
- Final feedback session with co-researchers
- Dissemination

Figure 6: Time Line for the Study

4.4. Phase 1 Reconnaissance Phase

Phase I included introductory sessions with the co-researchers and a reconnaissance phase. As recommended by Titchen and Binnie (1994) the reconnaissance phase aimed to ground the action-research cycles in the issues around participation in the area (see chapter 3). The reconnaissance study helped to meet objectives 1 and 2.

4.4.1 Early Action-Research Sessions

The phase included five introductory and exploratory sessions of the action-research group. The issues covered in these sessions were:

- Discussion, adaptation and agreement of the aim and objectives of the study
- Exploration of the meanings of participation with input from literature and theory
- Discussion of the motivations for encouraging participation within the programme

- Discussion of the root causes of constraints to participation from both the community and agency perspectives.
- Design of the reconnaissance study
- Analysis of reconnaissance study findings
- Development of techniques for measuring participation

These sessions provided data to meet objectives 1, 2, 3 and 4.

During these sessions the group often split into two and were facilitated using participatory techniques, such as flow diagrams and problem trees, to think through the constraints, enablers and motivations for participation. Games or 'energizers' were also used to help the co-researchers to get to know each other and develop strong ties.

4.4.2. The Reconnaissance Phase

The tools for use within the reconnaissance phase were designed by all the co-researchers. I provided some basic training for the group in research methods and we were then able to agree on the most appropriate way to conduct the study. We decided on semi-structured interviews with agency staff and questionnaire-based interviews with residents. While I played a greater role in developing the initial interview guide and questionnaire, the other co-researchers - particularly those resident in the area - were invaluable in refining both the design and tools to make sure they would be appropriate for use with residents. For example, while I initially suggested conducting semi-structured interviews with both agency staff and residents, the other co-researchers felt that some residents might find it hard to engage with the issue of participation when faced with open-ended questions. So we decided to use a simple questionnaire as a trigger for more detailed discussions. The approach worked well in practice and allowed us to present some quantitative data as well as the qualitative findings. While the number of questionnaires conducted was relatively small and certainly not representative, this still seemed to give the other co-researchers greater confidence in the data we had collected.

The agency staff were selected purposively by the co-researchers to seek out "information-rich cases" (Patton 2002). The aim was to illuminate experiences of encouraging participation within the main stakeholder organisations of the programme. Hence, two representatives from the primary care trust, two from the regeneration scheme, one from the city council, one from a local voluntary group and one from the local school were interviewed.

The residents were selected from three stratified groups; those that were actively participating in community groups in a decision-making capacity, those attending parent support and toddler groups and those that had had some contact with the programme but were thought to be isolated and unlikely to join in activities. However, within these groups the residents were selected primarily for convenience. While such an approach would be inappropriate for more conventional qualitative studies, it must be remembered that for the reconnaissance study the aim was to quickly gather just enough data to guide the subsequent action research cycles. Thus a more rigorous and in-depth qualitative study would have been too time consuming and unnecessary given the aims of the action research group.

The reconnaissance study consisted of 7 interviews with agency staff and 15 questionnaire based interviews with parents. The characteristics of the parents interviewed are given in figure 7 below:

Figure 7: Characteristics of Patients Interviewed during the Reconnaissance Phase

Characteristics	**Numbers Interviewed through questionnaire**
Age Range	19 to 25: n =7 26-30: n = 3 31-40: n =2 Above 40: n =3
Gender	Female n = 15
Housing Type	Tower Block n = 4 Walk-up block n = 7 House n = 4
Rented or Private	Private n = 3 Rented n = 12
Up-the-hill or Down-the-hill	Uphill n = 9 Downhill n = 6
Number of children per household	Range: 1 to 6 children Mean: 2.5
Degrees of Participation	Attending group sessions: n = 10 Active member of community/regeneration groups: n = 3 Programme contact, but isolated: n = 2

All the interviews were conducted by myself and one other co-researcher. Only 2 of the co-researchers, the health visitor and programme coordinator, were unable to commit the time to conducting the interviews.

4.4.2.1. Co-Researcher Reflections on the Reconnaissance Phase

I was concerned that this initial phase, with its interviews and questionnaires, would be seen by the co-researchers as too long-winded and academic. However, this phase proved to be interesting and motivating to the co-researchers, particularly those that were able to play some part in data collection. For the more junior co-researchers conducting interviews seemed to boost their confidence to raise and debate issues within the action-research group. As one said:

> "I really enjoyed doing {the interviews} - it was really good fun. And it sort of opened my eyes to how many people just don't know what is going on and their feelings about joining groups and their own lives" (Co-Researcher Interview during phase II).

So while the primary aim of the reconnaissance study was to gain just enough data to guide the subsequent action research cycles, it served the dual purpose of enhancing the confidence and engagement of the co-researchers.

Where possible, the interviews were recorded; however many of the residents and one agency staff member were not comfortable with this and detailed notes were taken instead. As there were two interviewers this did not prove too difficult. The recorded interviews were transcribed as soon after the event as possible. The analysis of this phase is described below in section 4.7. A user-friendly briefing paper was produced by myself and adapted by the co-researchers, documenting the key findings of this phase (see appendix 5). This was disseminated to all those that had been interviewed and to others within the regeneration scheme and health trusts.

4.5. Phase II

The early sessions with the co-researchers and the reconnaissance study in Phase I highlighted many of the blocks restricting residents' full participation. The co-researchers discussion of the blocks and analysis of the problems from both the agency and community perspective formed the foundation for the action research cycles of phase II. During this phase the group met 11 times. Attendance was good at all the meetings; only one co-researcher – one of the locality family workers – had to miss several sessions due to ill health.

4.5.1. Action Objectives

The initial sessions of this phase drew on the reconnaissance study findings and discussions of phase I in order to develop action plans for encouraging participation. The action plans had three main objectives:

1. To improve information about services and how community members can get involved
2. To establish feedback systems where service users can give compliments, complaints or suggestions on how to improve services and service providers act on and respond to their feedback.
3. To strengthen community participation in the decision-making structures within the programme.

The co-researchers working within the programme then used these action plans to guide their work. The action-research group offered them a forum for discussing their ideas of how to implement these plans. The group also helped with practical tasks such as designing feedback forms or creating posters for parents' views for use at feedback events.

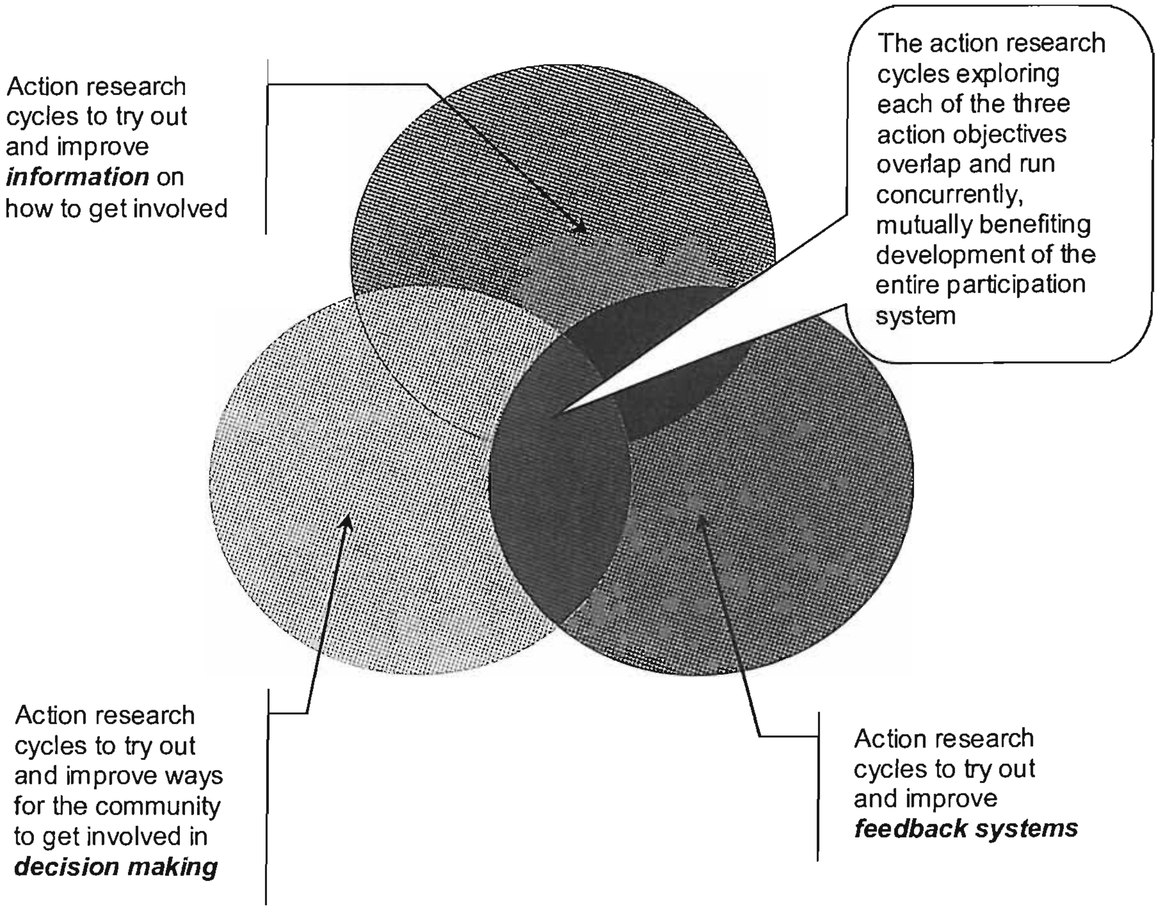
Figure 8: Action Objectives, Strategies and Observation Methods

Action Objective	Action Strategy	Observation Methods
1. To improve information about services and how community members can get involved	• Newsletters • Leaflets and mail outs • Word of mouth • Bring a friend • Hand-holding • Targeting residents	• Annual review survey and drop-in sessions • Interviews with residents • Observation at clinics • Feedback from co-researcher staff
2. To establish feedback systems where service users can give compliments, complaints or suggestions on how to improve services and the service providers can act on and respond to their feedback.	• Annual review • Texting • Phoning the programme coordinator • Feedback forms • Comments book • Feedback events • Attending working groups • Discussion with managers	• Annual review survey and drop-in sessions • Interviews with residents • Observation at clinics and feedback events • Observation of comments book • Feedback from co-researcher staff • Feedback from Church's family worker on texting service.
3. To strengthen community participation in the decision-making structures within the programme.	• Parents' panel (forum for encouraging parents' involvement in decision-making in the programme.) • Review of programme sub group	• Interview with residents • Feedback from staff involved with parents' panel and sub group.

4.5.2. The Cycles

As Chapter 3 notes, the action research literature often presents the process of action research as clear cycles or spirals (Carr and Kemmis, 1986; Reason and Bradbury, 2001); Hart and Bond, (1995) talk about a more complex process similar to an inter-twined Russian wedding ring. This was certainly the case with this study. Much of the action happened concurrently as did the reflections and observation. For example strategies for improving information on how community members could feedback were developed over the course of the year, starting with leaflets then developing appointment cards with details of programme telephone numbers and writing short articles for local newsletters. The effectiveness of these strategies was observed at different points throughout phase II including during a broader review of the locality family worker service, observation at clinics, feedback from relevant staff and interviews with residents (see Figure 8 above). Reflecting on these observations also helped in the development of feedback forms and events, hence the action-research cycles that explored information improvement ran continually throughout phase II and intertwined with the cycles exploring the other two objectives of feedback and of involvement in decision making. This concurrent and intertwined flow of the action research cycles is represented in Figure 9 below.

Figure 9: Interconnected Action Research Cycles



4.5.3. Observation

As Figure 8 shows, the action research group devised a number of ways of observing the effectiveness of the action strategies (Objective 2). The details of each of these methods are given below:

4.5.3.1. Annual Review

As part of the commitments of the regeneration funding, an annual review of the locality family worker service was requested by the regeneration programme. There were no specific guidelines on how this should be conducted so the action-research group were able to design the review as we felt was appropriate. We felt strongly that the review should focus on the clients' perceptions and experiences of the locality family worker service. After much discussion, a survey was decided on as the best way of gaining an overall view of clients' satisfaction with the service. We used several of the action-research sessions to design the questionnaire. While the questionnaire focused on all aspects of the service, we were able to take the opportunity of including a question to determine how effective our strategies at increasing information about how to feedback had been. The questionnaire had a surprisingly high response rate; 56 questionnaires were sent out to all the existing and past clients of the locality family workers and 25 were returned. This may have been because the clients were offered entry into a prize draw for a supermarket voucher.

We were also keen to use the review as an opportunity to engage with users on a deeper level and to gather more qualitative data on their experiences of the service. There was much reflection on organising previous group sessions for clients and real concerns that very few clients would turn up.

> "Practically I'm just imagining the poor person we put in there just sitting there alone with one person turning up... everyone saying 'ooh yeah we'll come' and then one person turns up; especially if it's nice day or something." (Action Research Session 10)

The group brainstormed possible solutions and ways to attract clients to attend. They agreed on the need to hold two sessions, one up-the-hill and one down-the-hill, providing child care support, toys and a light lunch. It was also felt that by holding a drop-in session rather than a group meeting, clients would be less apprehensive of group interaction. To help the clients to talk through their concerns to someone not directly involved with the service, the resident member of the action research group agreed to conduct very informal interviews and write down any key points to be raised with the service.

As expected by the group, the turn out to the drop-in sessions was small, in total five residents attended both sessions. While the topics discussed in the drop-in session were about the service more broadly, the process of observing what encouraged and what restricted participation of residents in these sessions provided the co-researchers with valuable lessons for designing similar sessions for the future.

So while the drop-in sessions were initially a method for evaluating the effectiveness of all aspects of the locality family worker service including the strategies for encouraging participation, the process of conducting the review through questionnaires and drop-in sessions also provided insights on these techniques as strategies for encouraging feedback and participation. The reflection on the strategies is given in Chapter 6.

4.5.3.2. Observation and Feedback from Staff

Throughout the action research cycles various methods were used to work with other aspects of the programme and to discuss how well the action strategies were functioning within their area of work. For example several meetings were held with the midwives to explore the extent of involvement and participation within their programme (using the Wheel of Participation described in section 4.6 below). This resulted in the development of a feedback form for parents using their advice and support group. Finally observations at the support group and telephone discussions with the midwives provided the feedback on the uptake and value of the feedback forms.

The programme coordinator, health visitor and locality family worker staff were able to feed-back their observations on the success of other components of the system during the action research sessions. These included the number and content of the comments in the comments book, the response to mail outs of information, the use of the office phone for complaints and compliments, the type of comments on the feedback forms and the impact of raising client and community concerns with decision-makers and within working groups.

Another component of the system that was monitored throughout the action research cycles was the texting service. The service was established so that clients and the wider community could comment confidentially on family support services in the area. In order to maintain some distance from the programme, the service was run by the family worker from the local church. To monitor, reflect on and develop the use of the texting service, the church's family worker was invited to feedback to the co-researchers on the number of text messages he had had, an indication of issues they covered and how he had been able to either respond directly or feed the views into relevant decision-makers and working groups.

By drawing directly on the feedback from these service areas the co-researchers were able to respond immediately to the issues they raised. Often there was an additional benefit in that involving these other staff within the study helped to build ties between the different elements of the programme and to stimulate further thinking on participation within these other arms of the programme.

4.5.3.3. Final Observations

While staff observations on the effectiveness of our action strategies were vital as we developed our participation system, once the main components of the system were up and running, we felt it important to hear client and community views of the effectiveness of our strategies and to observe how some of these action strategies were being used. In order to do this, the group decided that I, along with the non-staff resident co-researcher should conduct several semi-structured interviews with clients and the wider community and observe the uptake of our feedback strategies at clinics and groups.

In all, 6 semi-structured interviews were held with residents during the final months of the action research study in June and July 2005. The clients and community members were chosen purposively to shed light on the experiences of residents with different levels of involvement. Those that were most active in the community were accessed through the parents' panel (a forum for encouraging parents' involvement in decision-making in the programme), those with some passive involvement were accessed through clinic and group sessions, and those facing greater constraints to involvement were accessed through the locality family worker client base. The following parents were interviewed:

- 2 clients of the locality family workers,
- 3 parents attending clinic and group sessions
- 1 parent involved in the parents' panel

Within these categories, there were certain constraints in sampling. For example, with the selection of family worker clients, it would have been ideal to interview clients whose family worker was not part of our action-research group as those with a co-researchers worker might well have heard about our participation strategies through them rather than through our information strategies. However although all staff members were asked to inform clients and ask if they were interested in being interviewed, it was only the clients of family-workers who were also co-researchers who agreed to be interviewed. This suggested that the co-researchers were much more active in suggesting the possibility of being interviewed to their own clients than the non co-researcher family workers were.

Another constraint within this final observation stage and the reconnaissance study was that all the parents that were interviewed were women. This is a reflection on the lack of involvement in men in parental support activities. For example, it is very rare for a father or male guardian to attend one of the support groups or clinics, the locality family worker clients are all female and there are very few men that get involved in family support activities in the area. Clearly the processes used in these key observation stages of the study for accessing and gaining the consent of interviewees were very biased towards women. In recognition of this, the co-researchers made a concerted effort to discuss issues of involvement informally with fathers and guardians at community events. These views and opinions were then discussed within the action research sessions and eventually led to plans for the establishment of a 'Dad's group' within programme.

All the interviews were conducted by myself and the non-staff co-researcher following an interview guide. With the permission of the interviewees, they were all recorded and transcribed. During these interviews and subsequent meetings and visits to the relevant venues, notes were taken regarding the availability and accessibility of leaflets on how to get more involved and to give feedback to the relevant service arm of the programme.

4.5.4. Data on the Experiences of Encouraging Participation

In addition to the observation data to assess the effectiveness of our strategies for encouraging participation, a crucial part of the study was to collect data to shed light on the overall experience of attempting to implement the strategies in practice (Objective 4). In order to collect this data, I recorded and transcribed all the action research sessions from phase I and II. In order to encourage more in-depth and individual reflections from each co-researcher, I conducted one-to-one semi-structured interviews with the co-researchers half way through the study using a guide. This data, in conjunction with the observational data and findings of the reconnaissance phase were combined to shed light on the factors that help and constrain the programme in improving systems of feedback and the extent and quality of participation. The findings from this overall analysis are given in Chapter 7.

4.6. Measuring Participation

4.6.1. The Participation Wheels

As described in Chapter 3, the concept of measuring participation was felt to be a valuable area to explore within the study (Objective 3). Drawing on Rifkin et al.'s (1988) design and the characteristics of social audit as identified by Burns and Taylor (2000), I presented the concept of a participation ranking tool to the action-research group with the idea of using the approach with different stakeholder groups. After some discussion we agreed to amend the arms of the diagram and to name it the 'Participation Wheel'. We agreed that the most important stakeholder groups to do their own ranking were parents, the community health working group, the family support sub-group and the action-research group.

I was able to facilitate these groups to conduct their own ranking exercises as an agenda item within their existing meetings. For the residents, we asked parents attending a parent and toddler play group if they would like to carry out the ranking exercise as a group. Clearly these residents are the more confident and active members of the community, hence the views they expressed during the ranking exercise will be very different from the most isolated and under-confident parents.

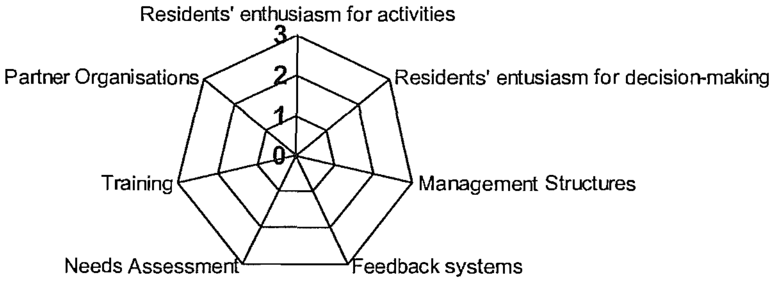
In order to get an idea of change over time, the participation wheels were repeated after 9 months; the first round of ranking sessions took place in May/June 2004 and the second round in February/March 2005. Two sets of wheels were produced by the Community Health Working group, the co-researchers, a group of parents and the co-researchers. The Programme sub-group, was only able to produce one participation wheel as the group was no longer meeting by 2005. The results of these Wheels can be found in Chapter 6, section 6.4.2 along with a discussion of their value and purpose.

The arms of the wheels cover seven areas of the design and management of the programme and the attitudes of residents. These areas were developed through a brainstorming exercise in one of the action research sessions. They are:

- Residents' enthusiasm for involvement in activities
- Residents' enthusiasm for involvement in decision-making about their community
- Management Structures(i.e. how open management structures are to community involvement, do they include practical support like child-care, expenses etc)
- Feedback systems (i.e. the existence of systems for clients to give their views and for these to be responded to)
- Needs Assessment (i.e. community involvement in the initial needs assessment)
- Training to support participation (i.e. to build self-esteem or chair meetings)
- Partner organisations support for participation (i.e. conducive policy environment)

Each of the arms of the wheel are divided into three, with one being the lowest level of participation and three being the highest level of participation (see figure 10 below)

Figure 10: The Wheel of Participation



4.6.2. Group Attendance Data

In addition to the participation wheels, the group were keen to see if there was any change in the numbers of people attending family support related groups and services. We agreed to collect data for two snap-shot months in order to keep the workload of collecting data to a minimum thus increasing the likelihood of the exercise becoming routine within the work of the programme, beyond the life of the action-research group. As planned, data were collected for months of June 2004 and January 2005 from a parent and toddler play group, the health visitors' clinic, a youth programme and a women's support project. The results of this data collection and a reflection on its value can be found in Chapter 6, section 6.4.1.

4.7. Analysis

Figure 11 below provides a summary of the data collected during the study, how it was analysed and by whom.

Figure 11: Data and Analysis

Study Phase	Data Collected	Method of Analysis	By Whom
Phase I Reconnaissance and Initial action research sessions (February to June 2004)	Transcripts and flip charts from 6 action research sessions	Framework approach (more inductive)	Researcher/facilitator (findings verified with co-researchers)
	Transcripts from 6 interviews with agency staff Field Notes from 1 interview	Framework approach (more deductive)	Researcher/facilitator and then co-researchers
	15 questionnaires plus notes from resident interviews	Descriptive statistics Framework approach (more deductive)	Researcher/facilitator and then co-researchers
Measuring Participation (June 2004)	4 participation wheels and notes	Notes included in framework approach	Researcher/facilitator and then co-researchers
	Attendance data from 4 services	Descriptive statistics	Researcher/facilitator and then co-researchers
Phase II Action-research Cycles (June 2004 to July 2005)	Data from annual review survey	Descriptive statistics	Programme staff and then all co-researchers
	Notes from drop-in sessions	Immediate analysis during action research sessions and captured in transcripts for later analysis using the framework approach	All co-researchers and then researcher/facilitator
	Notes from observation at feedback events	Immediate analysis during action research sessions and captured in transcripts for later analysis using the framework approach	All co-researchers and then researcher/facilitator
	Feedback from staff	Immediate analysis during action research sessions and captured in transcripts for later analysis using the framework approach	All co-researchers and then researcher/facilitator
	6 Interviews with residents (June/July 2005)	Framework approach (more inductive)	Researcher/facilitator (findings verified with co-researchers)
	Transcripts and flip charts from 11 action research sessions	Framework approach (more inductive)	Researcher/facilitator (findings verified with co-researchers)
Measuring Participation (January/Feb 2005)	3 participation wheels and notes	Notes included in framework approach	Researcher/facilitator and then co-researchers
	Attendance data from 4 services	Descriptive statistics	Researcher/facilitator and then co-researchers

4.7.1. Analysing Qualitative Data: the Framework Approach

As can be seen from Figure 11 above the qualitative data collected throughout the study were analysed by drawing on Ritchie and Spencer's 'framework' approach (in Bryman & Burgess 1994). The advantage of this structured approach is that the thematic framework can be closely based on the research objectives but also allows for other themes to emerge from the data.

Such an approach was vital as throughout the study the co-researchers needed data that could help to answer our objectives related to how effective specific techniques were at encouraging participation. Hence during the study the framework approach was used in two ways; firstly to analyse the qualitative data collected during the reconnaissance study and observational data collected during the action research cycles. Here the framework approach was used fairly deductively with key categories such as 'constraints to' and 'enablers of' participation which were derived directly from the objectives and formed the basis for the framework to identify specific techniques and approaches that either helped or hindered participation. Other more emergent themes were not explored at this stage as the main requirement of the data was to help in identifying specific techniques to encourage participation in the subsequent action research cycles.

In the second instance the framework was used more inductively to identify less obvious themes stemming mainly from the experiences of the co-researchers in attempting to implement the specific techniques to encourage participation but also from a more detailed analysis of the reconnaissance data. This more inductive approach led to deeper insights into the constraints to participation particularly in terms of organisational culture, structures, practices and staff attitudes.

To some extent this more inductive analysis of the data was initiated during the action research cycles, allowing for emerging ideas to be checked out within the group sessions and also during one-to-one interviews with co-researchers. The findings from this analysis were fed back to the co-researchers in a final session; this provided validation of the themes and also helped to highlight areas needing greater emphasis within the analysis and presentation of the themes.

The points below illustrate in more detail how each stage of Ritchie and Spencer's (in Bryman & Burgess 1994) framework approach were used for the analysis:

- Familiarisation: Here the analyst reads through transcripts and notes pulling out key ideas and starting to identify recurrent themes. This stage was done fairly rapidly for the reconnaissance study. After each interview I would discuss the key issues with the co-researcher who helped to conduct the interview. This also helped in identifying recurrent themes. For the second round of analysis I read through all the transcripts in some detail. Moreover, transcribing the interviews myself helped with further familiarisation of the data.

- Identifying a thematic framework: In this step of the process a framework is constructed based on issues from the original research aims, emergent issues from the participants and the recurrent themes identified during the familiarisation process. As explained above, the framework used for the reconnaissance study was based largely on the research objectives and only a minimal number of emergent issues were explored. For the second round of data the framework was developed more inductively based on emergent issues from the data as well as from the research objectives.

- Indexing: Here the thematic framework is applied to the data. For the reconnaissance data the indexing was conducted in 'Word for Windows'. To manage the data from the action research sessions and final interviews, the analysis package Nudist was used. This proved helpful in managing a large data set and also in adapting and developing the indexing and framework iteratively as the analysis progressed.

- Charting: this process involves lifting data from the original context and placing it within the appropriate thematic categories within the framework. Many of the themes for the charts used in this study were divided between resident, agency and co-researcher view points. This helped to compare different perspectives on participation. Part of this process also involved defining the themes and concepts within the chart. Again for the second round of analysis there was more time available to develop the thematic categories by working iteratively between the data and the themes and concepts than in the first round of analysis. (Some examples of the charts are presented in Appendix 6)

- Mapping and interpretation: The final stage in the process is to interpret and map the range, polarities and similarities within the data presented in the charts. During the reconnaissance study, interpretative maps were drawn as flow diagrams showing the inter-linkages between themes. I presented these to the co-researchers for discussion and together we interpreted the data. In the second round of the analysis the co-researchers were not directly involved in this part of the process as this was conducted after the main action research sessions had ended. However, a similar process of flow diagrams was used which was helpful in exploring linkages and searching for divergent data within each theme.

4.7.2. Analysing the Quantitative Data

The quantitative questionnaire data from the reconnaissance study were analysed using basic descriptive statistics. The co-researchers helped in identifying issues for cross-tabulation. For example, it was on their suggestion that we analysed the participation data in relation to whether the parents had children of pre-school or school age (5 years and above) children. A simple excel spreadsheet was used to work with the data.

4.8. Reflection on Validity and Rigour

Chapter 3 presents the debates on validity and rigour within action research. The increased validity gained from multiple observers and analysts was inherent in the design of the study which was based so fundamentally on a group of co-researchers. As described above the co-researchers were able to conduct interviews and observations as part of the study as well as play a role in the analysis of the reconnaissance study and observations throughout the action research cycles. The study used several different data collection methods which further add to the validity and rigour of the study (Patton, 2002).

The use of the cycles of the study to move between theory, research and practice has also been identified by Waterman (1998) as increasing the dialectic validity of the study. The discussions and debates among the co-researchers on their ideas and observations of establishing the feedback and influencing system can be said to represent the reflexive validity that is identified as important with action research.

The skills and behaviour of the facilitator/researcher have been identified by McNiff (1988) as important criteria for judging the worth of participatory action research. Naturally the other co-researchers would be better placed to judge my skills and behaviour as the facilitator/researcher, however to respond to these concerns, I kept a diary to reflect on group dynamics. This helped me to identify how effective various facilitation styles were in responding to potentially disruptive group dynamics and encouraging more equal participation among the co-researchers. Moreover, when conducting the individual interviews with co-researchers I asked for their feedback on my facilitation style and any suggestions for improving the way we ran the sessions.

The continual process of critical discussion within the group further enhanced the validity of the study by helping to bring biases to the fore. For example, interviews with agency staff in the reconnaissance study showed whole-hearted support for participation; it was only when the action research group actually came to try to implement the concept that staff's underlying concerns about participation were discussed openly. This not only meant that we could search for solutions in practice, but also provided valuable findings which might have been overlooked if a non-interventionist quantitative or qualitative approach had been used.

While the co-researchers were able to collect, analyse and critically reflect on data throughout the study, the overall analysis of the action research process was not conducted as a group. Many of the ideas arising from this final analysis had been discussed within the group and through the individual interviews with co-researchers; however the co-researchers were not involved directly in the final analysis. In order to check the validity of my own analysis, I presented the themes to the group for discussion in a final feedback session. This stimulated much discussion among the group and while they agreed with my overall analysis, they did point to elements within several of the themes that they felt should be addressed in more detail. This proved helpful and has influenced my final presentation of the study. For example they felt I should give more emphasis to the challenges they perceived when working with a community in a deprived area, hence weight and discussion has been added to this theme within the final presentation of the findings and the discussion chapter. Furthermore, the co-researchers closely linked to NDC felt I should highlight the problems of communication between the regeneration scheme's own programmes and partners and mention the lack of a central, combined location for health services. These points have now been included within the findings and discussion chapters.

4.9. Transferability of the Findings

As discussed in Chapter 3, section 3.10, transferability or 'external validity' as it might be understood within a positivist paradigm, refers to the possibility and limitations of applying the study's findings beyond the context in which the study was done (Malterud, 2001). Ensuring rigour within the study design, transparency in the presentation of the action research process in practice and a detailed account of the context in which the study was conducted all help the reader to determine whether the findings of the research can be transferred to their own setting (Meyer, 1993; Titchen and Binnie, 1994).

Within this thesis the details of the action research design and process have been given to explain the data collection methods used, the levels of participation among the co-researchers (see section 4.10 below), the process of analysis and the discussion of the findings among the co-researchers. The section above describes the particular steps taken to maximise validity and rigour within each of the elements. It is hoped that this level of transparency enables the reader to appreciate the rigorous process used within the study to strengthen the validity of the findings.

Appreciating the context in which the study was conducted is vital if the reader is to be able to decide if the findings are transferable. Chapter 5 below begins with a description of the community living in the regeneration area, with particular reference to the community's social capital, i.e. networks, norms and social trust (Putnam, 1995). This enables the reader to appreciate some of the challenges the co-researchers identified as constraining their attempts at encouraging participation. Chapter 5 (section 5.2) goes on to provide details of the NDC regeneration scheme and the programme hosting the action research study. The objectives and staffing levels of the programme are explained (see figure 12) and the scheme's mechanisms for community participation are described in section 5.2.2. In order to maintain anonymity of the co-researchers, only an outline of their particular characteristics is given. These can be found in section 4.2 above.

The longitudinal nature of the study, spanning an 18 month period, has ensured that a considerable depth of understanding of the context and experiences of both staff and residents in the area has been achieved. The longitudinal style of the study allowed deeper perceptions of factors which enable and constrain participation to emerge, which it is hoped, increases the value of the findings to those in similar contexts.

4.10. Type of Action Research

Chapter 3 outlines the spectrum of action research as identified by various authors (Holter & Schwartz-Barcott, 1993; Hart & Bond, 1995; Dick, 1997; Badger 2000). In terms of clarifying the characteristics of this study, Hart and Bond's (1995) typology has proved to be the most useful due to the detailed descriptions of each type of action research. Hence, based on their typology, this study can be said to have fallen between the empowering and the professionalizing type.

According to Hart and Bond's (1995) criteria the study shares characteristics of the professionalizing type in that it has been led and predefined by professionals and the facilitator/researcher. The study aims to "identify causal processes" within the intervention, which Hart and Bond place under the professionalizing type but also to "change the course of events" which fits better under the empowering type (Hart and Bond 1995 p.43). Furthermore, the study was intended to raise the consciousness of all its co-researchers, enhance user control and shift the balance of power – all characteristics of the empowering type – rather than merely "enhancing professional control" – a characteristic of the professionalizing type (Hart and Bond 1995 p.40). These distinctions are helpful in understanding the nature of the study, particularly when considering issues of power and possibilities for equal participation within the group (McTaggart, 1997).

While there are clearly elements of the professionalizing type within the study, in its design the study leaned strongly towards participatory action research. It is interesting therefore to consider how far, in practice, the study fell within the key characteristics of participatory action research as identified by Reason and Bradbury (2001) and discussed in Chapter 3. For example, the focus of the study on improving participation within the programme can certainly, given the arguments expressed in the literature review (Chapter 2), be said to be worthwhile which is the first characteristic identified by Reason and Bradbury (2001).

The fulfilment of Reason and Bradbury's second characteristic of working collaboratively with the least powerful is more debateable. It could be argued that the co-researcher group should have been made up of the least powerful within the community, in short, those residents who are isolated and find it hard to participate. Instead the group was made up of staff of different seniority levels and a resident who could certainly be said to be active and confident before the beginning of the study. However, given that the study also aimed to change practice, it was vital to work with those within the organisation. In fact it could be argued that the action research group should have included more senior managers in order to make wider organisational changes more effectively.

There appears to be a tension within the participatory action research literature between working with the least powerful in order to facilitate their empowerment and attempting to change organisations for the benefit of the least powerful. To do the latter it would appear that there is a need to work with the more powerful as well as the least powerful. This fits well with Freire's (1972) arguments, as discussed in the literature review (Chapter 2), of the need to raise the consciousness of both the 'oppressor' and the 'oppressed' in order to move away from the destructive dichotomy of power between groups in society.

Reason and Bradbury (2001) also identify developing knowledge and changing practice as key characteristics of participatory action research. The following chapters discuss the changes to practice that the study helped to instigate and Chapters 8 and 9, the discussion and conclusions, explores how the study has contributed to the wider knowledge base. However, for participatory action research, influenced by Freire's (1972) concepts of 'conscientisation', developing knowledge refers not only to academic knowledge, but also to the knowledge and awareness of the participants – the co-researchers. The action research literature also draws on Habermas' (1972) theories of knowledge to recognise not only the representational knowledge found through empirical studies and theories, but also knowledge developed through critical reflection. During individual interviews with the co-researchers they often mentioned how they felt they had developed a greater understanding of participation, both theoretically and within the context of the regeneration area. This learning appeared to come not only from the representational knowledge of the observation phases within the study and the theoretical inputs into the group, but also from having the space to reflect on these issues. The use of participatory techniques such as the diagrams shown in Figures 15 and 16 in Chapter 6 often helped to guide this reflective process.

Park (2001) further identifies relational knowledge as one of the components to help develop understanding within participatory action-research. This suggests that the interaction between the co-researchers further deepens the development of knowledge within the group. The most obvious example of this within our group was the value of the relationship between the non-staff co-researcher and the staff members. Her ability to challenge ideas and views and continually bring a perspective more in tune with client and community views contributed not only to the development of feedback and influencing system, but also to the knowledge and critical awareness of the group. One of the staff co-researchers explains this:

> "She {the resident member} gives a fresher view point really. She tends to bring a view point from the ground level – if you like. All us airy-fairy theoretical bods say something and she goes, 'no it wouldn't work...it's not like that!'" (Interview with co-researcher)

The relationship between the more senior staff and the junior staff was also an important feature of the group. Clearly the experience of the senior staff was a very valuable contribution to the group and helped us to design elements of the feedback and influencing system. However in many ways this can be seen as a double-edged sword. To a certain extent for some of the more senior staff, past negative experiences of trying to encourage participation had led to an attitude that most strategies had already been tried and there was little in point in trying again. On some occasions this attitude then bred a certain amount of negativity among even the most enthusiastic group members. Furthermore, the presence of more senior managers, particularly within the early sessions, appeared to restrict the participation of the junior staff.

> "{The line managers} can be a bit intimidating, not in a nasty sense, but just that they've got such a good grasp. Especially {one particular line manager}, she's got so much experience; I don't think I can compete with that. So sometimes it's easier not to say too much" (Interview with co-researcher).

Once again the relationship between the non-staff co-researcher and the rest of the group often helped to overcome this imbalance as she felt more comfortable than the junior staff in challenging more senior managers. Facilitation style was also important here and the use of smaller groups and participatory techniques and diagrams was beneficial in encouraging participation. Furthermore as described above, the involvement of the junior staff co-researchers in the reconnaissance study and other observation activities boosted their confidence and helped them to become more active participants in the group's discussion.

The final characteristic identified by Reason and Bradbury (2001) is that participatory action research should be emergent and flexible. In some ways elements of the study were predetermined, such as the use of a reconnaissance study and the overall time frame. These limitations to the flexibility were in response to the demands of conducting the study as a doctoral student requiring firm observational components to the study and having to work within a timetable driven by external funding arrangements. However, many elements of the study remained flexible and were able to emerge as the action-research cycles progressed, particularly the focus of the action objectives and the nature of the participation strategies. The study was also able to take advantage of existing work within the broader programme, in particular making use of the annual review as a way to evaluate the effectiveness of some of the participation strategies.

4.11. Reflections: My Role and Group Sustainability

As discussed in Chapter 3, there is some debate in the literature of the role of the researcher within the action research group. The role that I took was very much in line with the 'outsider' described by Titchen and Binnie (1993) as providing a diagnostic function and feeding back observations. However, an additional key part of my role was facilitating the action-research group throughout the study to analyse the different dimensions of participation and establish the feedback and influencing system. This facilitation role was particularly important in trying different styles and approaches to encourage the active participation of all the co-researchers. However, during the study I do not feel I was able to 'hand over the stick' (Chambers 1993) to the other co-researchers to facilitate and guide the group. While this idea was attractive, particularly in encouraging ownership by the co-researchers, the time frame for the study and the fact that it was designed as a piece of doctoral research severely limited the opportunities for doing this.

While the principles of empowering the other co-researchers to take greater control of the group were attractive, it must be said that at some points during the study, rather than wanting to 'hand-over the stick', I felt frustrated and wanted instead to take a stronger role in directing the group, as this exert from my reflective log suggests,

> "The session today just felt like we were going round in circles. It's been months since we started talking about setting up a group of parents, but still it hasn't happened. Maybe I should change the facilitation style and just become a little

> dictator giving everyone action-points to do before the next session? Gentle facilitation, always asking them to come up with their own ideas and action points just doesn't seem to get things moving" (Reflexive log book).

This frustration between wanting to speed up the group's progress in encouraging participation can be seen as a tension between the action and research elements of the study. If the study had been purely focused on action then a more directive approach, at least in the initial sessions might have been helpful. However, by maintaining a more facilitative role, leaving the co-researchers to come up with their own action points, the research element was able to explore the dynamics of encouraging participation within a community health programme in a more natural setting. If I had taken a stronger role in directing the group, the findings presented here would have looked at the experience of encouraging participation with the help of an outside worker, whereas due to the more facilitative role the experiences of encouraging participation are more in line with normal programme experience.

Interestingly, during the course of the study period my role went through a certain amount of change. While my role was to a great extent as an 'outsider', when the action research sessions were underway I was deeply immersed in the activities of the group. During this time I began the analysis of the session transcripts, this did help me to reflect on the dynamic of the group and the process as a whole, as did the use of my reflective diary. However, when the action research sessions come to an end and I began the analysis of the session transcripts in earnest, my role shifted from being an active co-researcher to being an observer looking down on the entirety of the experience of the group. In some ways this felt as if I was moving away from the participatory paradigm towards a more naturalistic, observational approach. However, it was only by extracting myself from the group that I was able to gain deeper insights into the processes at work within the organisations and communities of the study, this helped to shed light on the deeper organisational and attitudinal constraints to establishing a more participatory programme.

I was keen that the co-researchers should also be able to benefit from these insights and this was the purpose of the final feedback session. As described earlier this session led to some interesting discussions which have further influenced the findings and discussion. It is hoped that these insights will also influence the work of the programme. Furthermore, as the findings will be presented to senior managers within the health trusts and regeneration scheme, they may also influence service development on a broader scale. This can be seen as the final turn in the action research cycle.

After the final action research session, the co-researchers were keen to continue meeting on an informal basis in order to monitor and discuss progress with the feedback and influencing system. However, six months after the end of the sessions the group have still not met. This would seem to indicate that the central role that I took in facilitating the group and guiding its development, while it kept the group together during the study, may well have undermined the long-term sustainability of the group.

4.12. Ethical Considerations

The study received ethical approval from the local Research Ethics Committee in September 2003 (REC Reference 211/03/t). An extension to the period of the study was granted by the committee in order to carry out the final phase of observation. However, as Chapter 3 highlights there are some ethical concerns specific to action research. One of these is that due to the emergent nature of action research it is impossible for co-researchers to give truly informed consent as there are no guarantees of how the study will evolve. In light of this I emphasised the unpredictable nature of the study during the recruitment meetings. This may possibly have limited the number of staff who agreed to join the group, however it did mean that those who agreed to become co-researchers did so with their eyes open to the possibility of being part of a potentially challenging process.

Maintaining confidentiality has been challenging within the study, particularly because the regeneration programme is well known and the identities of the co-researchers are fairly obvious to anyone who works in the local area. In addition the co-researchers themselves were often keen to publicise the work of the group as they felt proud to be associated with a project working to encourage participation. Ownership of the outputs from the study has presented a further challenge, particularly in the context of a doctorate. In response to this, the advice provided by Lathlean (in De Reave 1996) has been followed by sharing publications and posters with the co-researchers for approval and discussing the overall findings at the final feedback session.

Summary

The approach used within this study can be said to have fallen within the professionalizing and participatory types on the spectrum of action research. The experience of working with this style of action research has provided interesting lessons in terms of the importance of facilitation styles and strategies for encouraging equal participation of all co-researchers particularly as they represent a variety of positions in terms of seniority and resident/non resident. The recognition of different types of knowledge within the study has also been important; the representational knowledge derived from the observation elements of the study and inputs from wider bodies of theory and literature were important, however reflective and relational knowledge were also significant in helping the co-researchers to move forward in the development of the participation system and in shaping the overall findings of the study. The following chapters explore the findings that have sprung from these mutually supportive epistemological groundings.

Chapter 5: Findings II: The Study Area: Characteristics, Interpretations and Motivations for Participation

This chapter begins with a detailed account of the characteristics of the regeneration area where the study was conducted. Details of the New Deal for Communities scheme's structures and mechanisms for community participation are given. After presenting these findings on the characteristics of the study site, the following sections look in more depth at the interpretations of participation and the motivations for encouraging participation. Firstly, the findings concerning the interpretations of and motivations for participation given by agency staff during the interviews held as part of the reconnaissance phase are presented. This is followed by the findings from interviews with community members held throughout the study – both during the reconnaissance phase and during the final observation stage. The reflections of the co-researchers on all these interpretations and motivations are given, followed by a final summary of the chapter.

5.1 Characteristics of the Regeneration Area

The regeneration area where this study was carried out is situated on the outskirts of a city in the South of England. The community was first established after a slum clearance in the late 1950s. Since then the area has, to a great extent, been left behind as the rest of the local area has benefited from both economic and social development. The area is physically divided by a steep hill. This has created 'up-the-hill' which consists of several high-rise towers and social housing and 'down-the hill' with social housing set in low-rise walk-up blocks and many private houses. A third demarcation is known as 'bungalow-land' which, as the name suggests, consist of bungalows many of which are privately owned. Forty-eight per cent of the properties in the area are local authority tenure, compared to 19% in the rest of the city (2001 Census, NDC).

As explained in Chapter 2, the multiple deprivation index is a useful way to measure the extent of deprivation in the area and was used as a key criteria for the selection of communities for NDC regeneration funding. The multiple deprivation 2004 score for the area where the study was located is 37.08. This falls within the 20% most deprived areas in England. In terms of health and disability, the area is within the 30% most deprived areas and does particularly poorly on education, training and skills where it ranks among the 10% most deprived areas in the country (Anttila et al. 2005).

The total population of the area is 9460, divided between 4100 households. According to the 2001 Census, the population is predominantly white, 97%. This means that there are fewer black and minority ethnic groups than in the rest of the city where 92% of the population is white. Given that the study was situated within a health programme aimed at supporting families in the area, it is important to note that the area has a higher number of lone parent households than the rest of the city. Between 1999 and 2003, the area also has a consistently higher percentage of low birth weight (i.e. under 2500 grams) babies (7.9%) than the rest of the city (7.1%) and England as a whole (6.3%). The number of teenage pregnancies is also higher than found nationally. From 1994 to 1996 the rate per 1000 was 9.7 in the regeneration area compared to 8.7 in the rest of the city (Stepping Out, 2000). The area also has high rates of mental illness, greater numbers of people suffering from illness and disability and greater numbers of people being admitted into hospital for heart disease than the rest of the city (Anttila et al. 2005).

The baseline data collected during the design phase of the regeneration programme also highlights some interesting aspects of community life in the area. For example, only 21% of residents felt that community members had any influence over local services compared to 25% in the rest of the city. Thirty per cent of residents in the wider city felt involved in community life, whereas in the regeneration area this was only 25%. Fewer residents (9%) in the area were involved in voluntary work than in the rest of the city (11%) and fewer (40%) felt there was a good sense of community, compared to 42% in the rest of the city (all figures from Stepping Out 2000). As described in the literature review (Chapter 2) Putman (1995) identifies the importance of “networks, norms and social trust that facilitate co-ordination and co-operation for mutual benefit” (Putnam, 1995 p.67) which he terms social capital. These figures show how limited some of the components of social capital, particularly involvement in voluntary work and community life and the strength of community ties are within the area.

5.2. The New Deal for Communities Programme in the Study Area

Given the characteristics of the area and its placement in the 20% of most deprived communities in England (Anttila et al. 2005), the area was selected for the government's New Deal for Communities regeneration funding in December 1999. This placed the area in the second tranche of NDC funding allocations. The first 15 months of the NDC programme were then spent carrying out a consultation phase, after which a bid document covering the five NDC theme areas – Crime, Living Environment, Education, Health and Employment – was submitted to Government Office South East. Currently in year 5, the £49 million programme is now in its second phase and has a further 5 years to run. A key component of the NDC approach is to work in partnership with the voluntary and statutory sectors. In practice this means that the funding provided by NDC is often matched or exceeded by statutory partners. It is hoped that this approach will further facilitate the 'mainstreaming' of the new programmes within the existing work of NDC partners such as the local city council and health trusts.

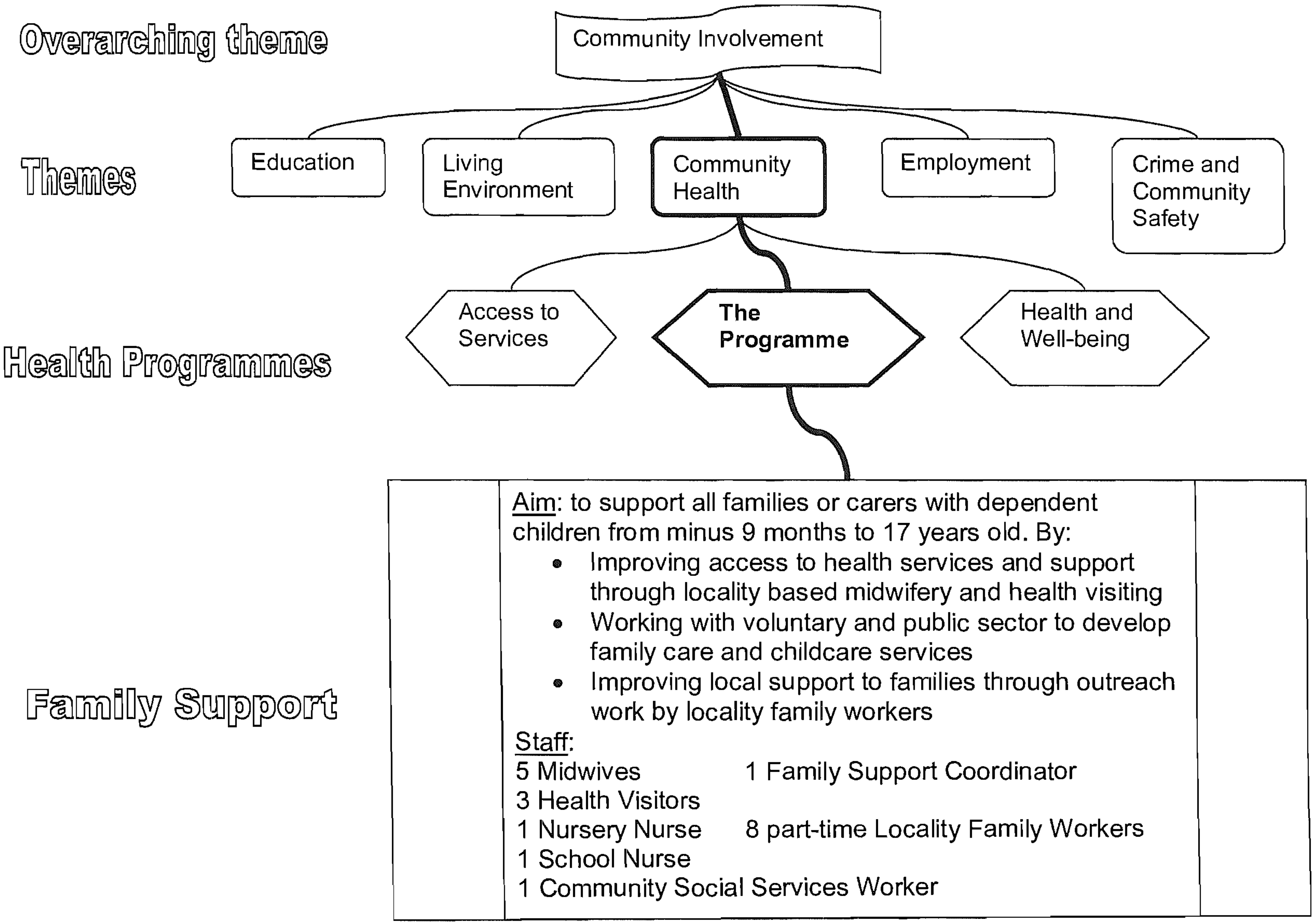
5.2.1. The Programme

The programme which hosted this study supports families in the area with children from before birth to 17 years of age, it is one of four NDC health programmes (see Figure 12 below for NDC themes and programmes). The programme draws on several strategies to achieve this aim of supporting families; a key part of the programme is the expansion of health visiting and midwifery services within the locality and the recruitment of eight part-time locality family workers to support their work. The programme is developing a range of groups and schemes to provide further support.

The programme is an example of the close partnership working between NDC and other organisations, particularly the health trusts and the city council. The health visitors and midwives within the programme team are managed and to a large extent funded, through the primary care trust and the hospital trust respectively. A proportion of this funding is provided by NDC. The locality family workers and the programme coordinator are currently funded by NDC but are managed through the primary care trust, there is a desire from both NDC and the trusts to mainstream these staff costs and line management within the core trust budgets, rather than relying on the relatively short-term NDC funding.

The locality family workers are a key component of the programme. Eight part-time workers were appointed in November 2003. Their role is to offer practical support to families with children aged 0-17 years old and to pregnant mothers. The support provided ranges from building family relationships, to information and advice on local groups and services, healthy eating and cooking on a budget, establishing and maintaining household routines, to signposting to relevant services and agencies. The idea is that this type of practical support can help to reduce the pressure on families so averting future crises. The family workers also support the health visitors, midwives and others in running parenting related groups in the area. The majority of the family workers have been recruited from the regeneration area, an initiative which stems directly from the ethos of NDC which recognises the value of local residents' knowledge and the importance of providing employment opportunities for those in the area (Programme Annual Report 2004-2005).

Figure 12: NDC Themes and Programmes



<u>Aim</u>: to support all families or carers with dependent children from minus 9 months to 17 years old. By:

- Improving access to health services and support through locality based midwifery and health visiting
- Working with voluntary and public sector to develop family care and childcare services
- Improving local support to families through outreach work by locality family workers

<u>Staff</u>:

5 Midwives	1 Family Support Coordinator
3 Health Visitors	
1 Nursery Nurse	8 part-time Locality Family Workers
1 School Nurse	
1 Community Social Services Worker	

5.2.2. Participation Mechanisms in NDC

One of the key themes of NDC's work is to enable participation of residents to work towards "an empowered community initially influencing and ultimately controlling and making decisions in relation to local services." (Stepping Out 2000 p.47). This theme runs throughout all areas of NDC's work. During the initial development stage of the NDC scheme a consultation process was conducted with the aim of listening to the views of residents, particularly those whose voices are seldom heard. A strategy document entitled Stepping Out (2000) was the result of this consultation which drew on the views of over 1500 local people and over 6,500 hours of discussions among community and agency partners of the problems and their potential solutions within the area (Stepping Out 2000).

Building on this process, several layers of discussion and decision-making bodies were established to develop, guide and monitor the programmes under each of the five NDC themes – education, employment, environment, crime and health. The ultimate decision-making body is the NDC Partnership Board, which meets every six weeks. The Board consists of 60% residents and is chaired by a resident member. The remaining 40% is made up of representatives from NDC partners within statutory agencies and voluntary groups. During the reconnaissance phase of the study many of the NDC agency staff expressed concern that the residents participating in the working groups and the board were 'the same old faces' and that while there was a committed core group of residents it was very difficult to get new members to attend. This would certainly seem to be borne out by the interviews with residents during the reconnaissance phase which showed greater participation from residents of 40 years or older, with several older children, living in private houses in the 'down-the-hill' area (for more details see appendix 3, Participation Brief II).

In order to extend the number of residents participating in the formal structures of NDC, an election process was held in 2004 to elect residents to the Board. Twenty-two per cent of the population turned out to vote for the 12 resident seats. The elections will now take place every year with 6 of the residents' seats being open for re-election; the other 6 elected residents remain on the Board to keep a degree of continuity on the new Board (NDC Delivery Plan 2005-2011 and personal communication).

Each of the five NDC themes has a working group with resident representation. The number of residents and their level of activity varies between groups. The Community

Health Working group has a core of four or five residents who regularly attend the group's meetings. The working group's main role is to develop project ideas and proposals and monitor progress of existing projects; they do not have decision-making authority for resource allocation but can make recommendations to the Board. The programme where this study was situated falls within the remit of the Community Health Working Group, but also has its own sub-group. Initially the sub-group, which included several residents, was very active in developing the project proposals for the programme. However during the implementation of the programme the role of the sub group has become less obvious. At the time of writing the remit for the sub-group is under review by the programme coordinator, it seems likely that the sub-group will be reformed to provide a networking function among local organisations working on family support issues.

Given the strong emphasis on participation and community engagement within the regeneration area, the following section presents the findings from the study to explore the motivations for and interpretations of participation as articulated by residents and agency staff.

5.3. Interpretations and Motivations for Participation

As identified in Chapter 2, there are a range of interpretations of participation both in the literature but also being played out in practice. Arnstien's (1969) ladder was one of the first expressions of these differing forms of participation and as highlighted in the literature review, these interpretations are often the result of underlying motivations for encouraging participation. In light of this, exploring the interpretations and motivations for participation was an objective (Objective 1) for the study and as such guided the interviews and analysis throughout the study, was discussed in depth by the co-researchers and explored further during the analysis of the action research transcripts and interviews with co-researchers.

This section presents the interpretations of and motivations for participation given during 7 interviews with agency staff during the reconnaissance phase. The following section focuses on parents' perceptions and motivations drawing on the 15 questionnaire interviews held during the reconnaissance phase and the interviews held with six residents during the final observation stage. The co-researchers' discussions of the different types of participation and how realistic these might be in the context of their programme are explored in section 5.4., with a reflection on the group's own motivations for encouraging participation.

5.3.1. Agency Interpretations of Participation

5.3.1.1. A Broad Spectrum

All the agency representatives interviewed emphasised a range of ways for the public to participate within their own particular service. There was some indication that these ideas have shifted over time and now even consultation, which many identified as a limited form of participation, was seen as a valuable mode of participation.

> "It's very complicated. I think there is a broad spectrum, not one definition. You could say that even when people recycle their rubbish they are participating, so there is a broad spectrum right up to unpaid volunteers; could be filling in surveys, attending public meetings. I understand it to be extremely broad. I can't say for definite, but in the past I think that there has been a very structured idea of participation which involves people getting on a committee. I think that has changed a lot over the last couple of years and it has been recognised that even low level participation, a quick bit of consultation, is as important" (Individual interview with statutory agency representative).

There was a sense from many of the agency staff that there was a real need for this broad range of ways to participate in order to remain relevant and appropriate to different people at different times in their lives.

> "Obviously where we're coming from we are trying to tailor how people become involved in a broad way that can change with peoples' lifestyles; there are times when people can commit a lot of time and other times when they're doing their own thing. So that's something we're looking at how to tailor different.... a sort of pick and mix" (Individual interview with statutory agency representative).

Furthermore, that the public should be able to choose the most appropriate level of participation for themselves.

> "Participation is a strange being. It should be a choice issue. They should be able to chose how much they wish to get involved and how much they can participate" (Individual interview with statutory agency representative).

5.3.1.2. The Ends of the Spectrum

While there was general agreement among those interviewed of this range of types of participation, there was less clarity about what the extreme ends of the spectrum looked like. For example this agency staff member identified information-giving as a minimal form of participation.

> "And there are types of participation, it can be very minimalist, like giving them information or at the other end of the scale you can have them making decisions about what should happen in an area and that's fuller participation" (Individual interview with statutory agency representative).

For the interviewee in the first quote in section 5.3.1.1 above, even engagement in civic responsibilities such as putting out the rubbish could be described as participation. Interestingly none of the agency interviewees identified attending support groups or state/voluntary run activities as participation. This is in contrast to the residents whose interpretations of participation are presented in section 5.3.3.1. There was agreement among the agency staff that consultation whether it took the form of surveys, 'visioning workshops' where participants wrote key issues on post-it notes, or talking to people in the post office queue, was still a valuable but limited form of participation.

There was concern among many of those interviewed that when used in isolation, consultation could be detrimental to relations with the community. This was particularly the case where there had been extensive consultation and a lack of involvement in decision-making. Where this low level of involvement was coupled with little tangible evidence of improvements there was a firm belief among many that this had led to a sense of disillusionment among the community.

> "The thing is when NDC started everyone thought, {the regeneration area} has got a lot of money, all these millions of pounds. But as people aren't involved in how decisions are made, then there are a few months when nothing happens, so there is a tide of cynicism that grows. And the longer you go without anything on the ground, the worse it gets" (Individual interview with agency staff, regeneration scheme).

5.3.1.3. Community Control: Differing Emphases

There was some variation among the interviewees in how they described the most participatory end of the spectrum. For the agency staff working for the regeneration scheme and for the voluntary organisation staff the highest level of participation was seen as being able to influence decisions.

> "I think the level of influence is really important. If you asked the previous question to many in the organisation, they would cite examples where residents are attending meetings. But I can't classify that as good practice, I see it on a deeper level" (Individual interview with agency staff regeneration scheme).

As discussed in section 5.2, a feature of the regeneration programme is that funding had been given to a specified area and its community. This has provided a boundary to demarcate who should benefit from the programme, this then provides clarity as to who should influence the decision making and delivery.

> "It's their {the communities'} programme. In many ways the money was given to them, they have requested this programme, it was their delivery plans. So really residents have got to have full influence" (Individual interview with agency staff regeneration scheme).

This chimed with the view of a local voluntary sector worker, who felt that,

> "The residents have got to be the main people making decisions" (Individual interview with community development worker).

For the one health agency staff interviewed there was a slightly different emphasis. Here the focus was on being able to listen to communities and then be responsive to their needs. While the idea of working *with* communities comes out strongly, there is less emphasis on residents actually taking decisions themselves. For example in the second quotation the interviewee stresses the importance of listening carefully to what communities want and moulding the programme to best fit their needs. However the programme is still seen as *belonging* to the organisation.

> "Any effective programme will actually require a level of engagement, not the old fashioned patronising, one size fits all, take it or leave it. The NHS has moved beyond that over the past few years. You can't expect people to be

> grateful for what you have provided for them. It's a very different kind of engagement. So involving and working with communities has to be the key to health and defining what the appropriate service is which people want to benefit from. (as below: Individual interview with statutory agency representative)

And

> "I guess it's whether you take as your starting point what communities tell you and listen and carefully see how closely you can get to what they are asking for or whether you start with what you believe you want to deliver and see how little you want to budge to keep the community satisfied… I'd strongly advocate the former. You start with that ambition and then you may have to modify things a little bit. Does mean you can't do everything as you intend when you started off. It's a question of where you start off, whether you are working *for* a community or *with* a community" (Individual interview with statutory agency representative).

While those within the regeneration programme were quick to admit that they had not been overly successful in achieving strong residential influence over decision-making, several of the regeneration staff interviewed appeared to aspire to go beyond merely moulding programmes to fit the community's needs. They talked of an ambition to move towards a situation where residents were setting their own agenda, rather than responding and modifying the ideas emanating from outside agencies.

> "What's going to be interesting is that we're moving to a more commissioning model. So we're empowering our Board to take centre stage and instead of leaving it up to agencies and partners in terms of what projects they bring to the table for residents to approve. The new way were heading, is that the residents on the board, who are the majority, drive the agenda so they make the strategic decisions about the areas of work they want to do and projects they want to see. Then pass that down and allocate authority to the themes for the best way to deliver on that. It will be more uncomfortable for the agencies and the partners but more empowering for the board and the residents" (Individual interview with agency staff regeneration scheme).

However, others within the regeneration scheme placed a stronger emphasis on partnership between agencies and residents.

> “We all know that actually you have to engage another agency to be able to deliver that programme and the PCT have their own rules and regulations, so there has to be that sense of compromise. Where residents have to be fully involved, but there has to be an acceptance on both sides that it’s a partnership between the residents, NDC and the PCT. If it works properly then everyone would be contributing equally to the relationship. So the PCT are not saying it’s our service and we’ll do exactly what we want, and the residents aren’t saying hey it’s our money, so tough. That’s not a good way to go” (Individual interview with agency staff regeneration scheme).

It would seem that there is some tension here, both for the partners and staff within the regeneration scheme, between placing residents ‘in the driving seat’ and developing a more equal partnership.

5.3.1.4. Parameters to Participation

While regeneration scheme staff appeared to see the extreme end of the participation spectrum as residents defining and driving the agenda within their own community, they also identified some limitations to the power of residents to do this. For example reservations were expressed about resident involvement in human resource issues.

> “I am very happy for residents to be involved in the recruitment of staff, but how you manage those staff once they are recruited, well then you start to get into lots of legal difficulties” (Individual interview with agency staff, regeneration scheme).

The issue of setting programme outcomes also raised some interesting questions about the extent to which the local community should be able to set the agenda. As explained in Section 5.2, at the inception of the regeneration scheme a fairly extensive consultation was undertaken culminating in the identification of key outcomes for the programme based on the community’s concerns (Stepping Out, 2000). However, by 2004 these outcomes had been reduced and streamlined to fit more closely with government targets. While these changes had received approval from the resident members involved in the programme, it does raise questions about how far residents can truly set the agenda in a government funded programme, with the need to hit central government targets.

> "I think a balance has to be struck between completely ignoring national outcomes and targets and saying there is no way you can not explicitly link what we are trying to do in {the regeneration area} with anything that is related to national targets. To go to the extreme to say this is only about delivering local aspirations and things valued by the local community, rather a boring answer, but there has to be a balance. The people that found the money in the first place for {the regeneration scheme} will expect to see things happen and having faith in the communities will also contribute to the national aspirations of these programmes" (Individual interview with statutory agency representative).

In summary, for the agency staff both within the regeneration scheme and its partners, there was clearly a broad range of types of participation. The interviewees had different interpretations of how each end of this spectrum might look in practice. Some interpreted the lower levels of participation as information giving, while others felt carrying out basic civic responsibilities could also be included. All were agreed that although consultation came towards the lower end of the participation spectrum it still had value but, if over-used with limited outcomes, it could be counter-productive by fuelling disillusionment among the community. At the other end of the spectrum those working for the larger public bodies emphasised the need to mould and adapt their programmes to the needs of communities. For those working in the regeneration area the aspiration went further than this by emphasising that residents should actually set the agenda and have greater ownership of programmes. However, even those in the regeneration scheme were clear that on issues of staffing the community should not be too closely involved. Furthermore, there were tensions of aspiring to greater community ownership within the context of a centrally funded programme with specific national targets.

5.3.2. Agency Motivations for Participation

The agency staff's explanations for their organisations' desire to encourage participation ran in a similar vein to that found in the literature (see Chapter 2). The key reasons identified from the literature are that participation can potentially make services more responsive to client's needs, increase sustainability and encourage community ownership of projects and build the skills and confidence of those who participate. When asked, some of the agency staff were able to cite examples where participation either by communities or users, had had some impact on services. The next five sub-sections discuss the motivations given by agency staff for encouraging participation in relation to the improvement of services. The remaining sub-sections present the motivations expressed by agency staff that relate to improving the lives of community members themselves.

Participation to Improve Services

5.3.2.1. More Responsive Services

The most common reason cited by agency staff for encouraging participation was to adapt existing services to be more responsive to the needs of users. This was also the area where staff were able to cite some examples of services that had been adapted in some way in light of either consultation or even deeper forms of participation. In the example below, a staff member from one of the partner organisations describes the process of participation used in one of the inner city streets and the way changes were able to be made to the existing service.

> "There are two that are going on at the moment. One is in the city – Residents' association. Which I think has been phenomenally successful....One of our community workers working in Social Cohesion decided to – it happened on another street successfully – to target that street, door knocking, conversations, not questionnaire but "what issues are affecting you at the moment?"
>
> A couple of meetings took place and the turn out was phenomenal. In one street there was a turn out of 30 people, that's great ..... what was particularly inspiring was that it wasn't just a moan session, where people say, 'what are you going to do about this?' It was, 'we have a problem with this, have you thought about doing this?' Then we would come back with a response that we had thought about it and it doesn't work for a, b, c then they came back again with another constructive idea and these were issues that they had been talking about among themselves and it wasn't a moaning session. It was – we've got some ideas and let's talk about it and it was really constructive and yeah, it was heated but in a good positive charged way, rather than just negative...... There were a couple issues, like reviewing the parking zoning issues, so they've had a very clear result. They've turned up to two meetings and someone from parking has put their ideas into practice in a trial period. He'll go back to them to ask them whether it has worked. So it's a close dialogue between officers and residents" (Individual interview with agency staff, partner organisation).

A further example was cited by one of the health partners to the regeneration scheme, showing how consultation has influenced the design of health services.

> "So defining the follow up work for people {who have had heart attacks}, they've told us that they find it very helpful to have someone come to their home when they are recuperating out of hospital. It would be very easy to say, 'no, that's not the way we do it you have to go down to your doctors'. But we've adapted that to what people said and managed to set up a service so people can be visited at home. Many people told us they found it helpful to have a phone number or somewhere where they could drop-in for further advice. So now we have a drop-in clinic run by a cardiac nurse and they can use that anytime in the first few weeks and months after coming out of hospital" (Individual interview with agency staff, partner organisation).

The staff working for the regeneration scheme were also quick to point out the benefits of hearing and responding to the views of local residents in order to make services more locally appropriate. Here a staff member describes the impact of involving a local foster parent in the discussions to design a new fostering scheme in the area.

> "The idea was to encourage fostering in the area to create more placements for foster children in the area.... So they thought of more foster parents here and then we had a foster parent involved in the discussions about the project. She said it could actually be quite awkward being a foster parent of a family just down the road like that. It would be better if it was some kind of respite care. Like a granny or favourite aunty to take the steam out of the situation while the family gets sorted and then the child goes back quite quickly. That's more what social services want, they don't want people split up where things can break down more and more." (Individual interview with agency staff, regeneration scheme)

These examples show a range of levels of participation including meetings with residents, dialogue with users and the inclusion of a foster carer within a planning meeting. It is interesting to note that the staff member from the regeneration scheme was able to cite an example where a resident, albeit a resident with fairly specialist skills, was able to influence the programme during the design phase. While the initial concept may have originated from the agencies, at the very least a community member has been able to influence the early design of a service, rather than merely 'tweaking' an existing service. So it would appear that for staff within the regeneration scheme and its partners, the contribution of community members to the design and improvement of services was seen as valuable.

5.3.2.2. Ownership and Sustainability

A further motivation for involving local residents or users within the design and development of services was the hope that it would stimulate ownership of the programme. There was also a sense that by increasing levels of ownership the programme, or some element of it, would have more chance of surviving to its end and possibly beyond.

> "It is one way of making things more sustainable. If you have a service coming in and doing whatever and local people aren't involved or know why or how it was done, then it's just something that happens to them and then goes away again, until the next fashion comes along. This way we hope that people will have an ownership of what is happening" (Individual interview with agency staff, regeneration scheme).

Unfortunately no examples of a long-term sustainable programme based on community ownership were given during the interviews; however this may have been due to the relatively recent policy shift towards encouraging consultation or deeper participation.

5.3.2.3. Better Value for Money

An interesting motivation for participation given by one member of staff working with the regeneration scheme was that the inclusion of residents within the project appraisal process had encouraged economic efficiency. Although, it was felt that residents would not have the capacity to scrutinise large sums of money.

> "I think anyone that has been around the block in local regeneration, community development work have proven to themselves that there are sound reasons for involving people. It could be around spend, in that projects are better value for money when people who have scrutinised it are more in touch with what a pound is worth. It's different if you're earning £50 or £70 grand a year and you are used to signing off £5 million of projects, then you don't scrutinise it. I find that local people get involved and they can make decisions about sums of money they can get their head around. So applications for £3 or £4,000 they will

> scrutinise that because they can understand the figures. But you put a million pound project in front of them and they're stuck" (Individual interview with agency staff, regeneration scheme).

However, none of the other interviewees identified value for money as a motivation for encouraging participation. Conversely several others pointed to the increase in officer time needed to work through the regeneration scheme's processes which have been established in order to involve local residents.

> "It has been remarked when projects come back to appraisal that they have been gone through with a fine toothcomb, before getting to that stage. The frustration from the services point of view is that it takes a lot longer and I've had to do a lot of explaining to our partners about the nature of what we are trying to do and saying, 'no its not SRB6 {Single Regeneration Budget 6}' and they have to engage with the residents and go through this process, and 'yes it is very torturous and isn't it awful but I'm afraid this is how its done!' They've found that very difficult as it has meant a lot more officer time and it's not time they are used to giving up so it's very difficult from their point of view too. We talk about voluntary effort from residents, but there has also been a lot of voluntary effort in terms of the officers as well" (Individual interview with agency staff, regeneration scheme).

It could be argued that this increased workload is related to the schemes' processes rather than the inclusion of residents within the decision-making structures. As none of the other agency staff pointed to greater economical efficiency because of increased levels of resident or user involvement, this evidence alone is not enough to identify economic efficiency as a serious motivation for agencies.

5.3.2.4. Communication

For the regeneration scheme a key issue was communicating with residents, this is linked to an awareness of the discontent of many residents who feel that few tangible benefits of the regeneration can be seen. For many of the staff this caused frustration as they felt that much was happening that the residents were unaware of. Hence, involving residents was seen by some as an ideal way of opening these channels of communication with residents. For example when talking about a new scheme of representatives in each block of flats, one of the agency staff explains its' value as:

> "A way of influencing the gossip and the communication, we can feed them what the real picture is and then when they hear the negative stuff, they can say, 'well no actually they're {the regeneration scheme} doing this'" (Individual interview with agency staff regeneration scheme).

This interviewee did also talk about the value of participation as a means to developing empowerment and the importance of developing agency structures that were open to influence by residents, however this statement would appear to point to an emphasis on improving the public image of NDC rather than listening to the concerns of residents.

5.3.2.5. Policy and Politics

A clear motivation within the regeneration scheme for encouraging participation was the fact that a key element of the scheme, as stipulated in government policy, was to build community ownership through developing a resident-led programme.

> "Its part of the doctrine really nationally that NDC are meant to be resident-led. Because good practice shows that historically regeneration programmes have failed because it's the same old service providers doing the same old thing with a new pot of money. So get the local people involved and they can challenge those ideas and come up with new ideas. So it's built in from central government" (Individual interview with agency staff, regeneration scheme).

However, there were concerns expressed by several of those interviewed that the underlying motivation for this policy direction was purely an issue of presentation with the aim of accruing strong political capital.

> "In terms of the government, the theory is that it {participation} is democracy in its pure form, the reality is that it is probably more to do with politics. If you get people involved it looks like we are a caring sharing government" (Individual interview with agency staff regeneration scheme).

The suspicion that government motivations may be more to do with politics than a firm belief in the benefits of participation for regeneration led to a perception among some of the NDC staff interviewed that the willingness to establish and support participation as a fundamental way of working with the programme was lacking.

> "Right from the very top you have this barrier stopping people getting involved. So it is a political problem. If you want people to participate you have to set up all the processes to allow them to participate fully. Making sure there is proper money to train them up to participate to a proper level" (Individual interview with agency staff regeneration scheme).

Participation to Improve the Lives of Community Members

The agency staff interviewed also expressed a desire to encourage participation as they felt it was directly beneficial to those participating.

5.3.2.6. Building Skills and Knowledge

A common response by agency staff when asked why they wished to encourage community participation was as a way to increase the knowledge and skills of residents and users. Some initial training on health issues and organisational processes had been provided for those involved in the health working group and the member of staff responsible felt this had been beneficial to the residents.

> "Feedback from them was that they were really gratified by the knowledge they had gained and they understood things a lot more. We've had a couple of training days for the health working group and that is the kind of feed back I've had on the process that everyone is more aware now of things than they were before" (Individual interview with agency staff regeneration scheme).

One respondent pointed out that often resident's lack of knowledge was a disadvantage when they were participating in discussion and decision making groups. Here the knowledge being referred to is officially recognised health or organisational related knowledge. It is interesting to note that none of those interviewed specifically mentioned the value of local knowledge or experience or identified accessing this knowledge as one of the motivations for participation.

> "In terms of the agencies, they have got to feel they have a voice anyway. The thing is we really need the agencies there to actually 'up' the debate because residents not having that specialism are not fully aware of all the implications, so we need the agencies there to bring that out in debate. So because, when we are talking about participation it is also about gaining knowledge and that's a very big part of it and so the agencies are there to actually impart that" (Individual interview with agency staff regeneration scheme).

This quotation gives an insight into the character of the working group meetings with agency staff and residents. It would appear that the focus and structure of the meetings is orientated towards the agency agenda which the residents need skills and knowledge to be able to engage in. This is interesting when compared to the participation literature particularly the focus on valuing local knowledge and community members setting the development agenda.

5.3.2.7. Empowerment and Community Building

Linked to the issue of raising skill levels was the issue of empowerment and self-esteem.

> "Its about giving people skills to get into employment and develop their own career paths, or could be having a bit more ownership in the community or building up a bit of self-esteem. What is quite common is that people start to look back and say I can't believe I did that – I couldn't have stood up in front of 400 people and done that. I would suggest it is mostly building self-esteem" (Individual interview with agency staff, partner organisation).

There was also recognition that for a real sense of empowerment, those that get involved would have to see a tangible change and improvement.

> "If the organisation listens to what they're saying and acts on it, there is real empowerment there that they changed a service or developed a project and that's a positive. And it builds community by working together, joining up with a neighbour or friend and pulling together. I think there are lots of benefits; directly that they're changing where they live and the involvement benefit of interacting socially and there is the academic and learning that they pick up and

> the empowerment bit" (Individual interview with agency staff, partner organisation).

Through this process of working together this respondent also identifies benefits in terms of strengthening social networks and bringing the community together.

5.3.2.8. Individual Responsibility for Health

One of the health partner staff also felt that participation – which was described as working with people – could be used as a way to encourage people to take responsibility for their own health.

> "Well you could say that the PCT is just here to provide services, but that would be to misunderstand all its' roles and its' key mission and aim to improve people's health. If you say it's about providing services, then it is about doing things to or for people. But I think it is fundamentally different when you are talking about improving health, you should be working with people as health is their own responsibility to some degree" (Individual interview with agency staff, partner organisation).

The implication here is that by working closely with individuals in the community this can help them to start to make changes to their own lifestyle and hence improve their health.

In summary, the motivations for encouraging participation expressed by agency staff fall into two categories; those that can be seen to benefit the effective implementation of the programme (hopefully to the ultimate benefit of the community) and those that benefit the individuals themselves that participate in the programme. The following section presents the interpretations of participation given by residents followed by an exploration of their motivations for getting involved.

5.3.3. Parents' Interpretations and Motivations for Participation

The parents' interpretations and motivations for participation presented here come from an analysis of the interviews conducted during the reconnaissance phase and the final observation phase (see Figure 11 in Chapter 4 for a summary of data collected and analysis approaches). As described in Chapter 4 the parents interviewed were purposively sampled to explore different perceptions among those that were more actively participating and those that were isolated and rarely involved in any community activities.

5.3.3.1 Interpretations of Participation

The majority of those interviewed were involved in fairly limited forms of participation. In general they interpreted participation as attending groups or joining in activities. As many were parents with young children this meant getting involved in activities for their children and joining parenting groups. In particular they mentioned attending parent and toddler groups, baby-care groups, breakfast clubs at local schools, sports activities and outings to local attractions organised by community organisations and the regeneration programme. This form of participation can be said to sit fairly low on the participation spectrum, so this group are referred to here as 'passive participants'.

It was only those who were already very active in the community that understood participation as getting involved in making decisions or designing of services. This group are referred to here as 'active participants'. This group made up the minority – only 4 - of the total number (21) interviewed in the reconnaissance phase (15) and the final observations (6). Their participation ranged from running parent and toddler groups to active membership of the working groups of the regeneration scheme.

The passive participants only talked about giving views or joining decision making groups when specifically asked. The interviews did not explore in depth why these parents only associated participation with joining activity or support groups. However, during the reconnaissance study, when asked directly 7 out of the 15 parents interviewed did express an interest in participating in regular decision-making meetings associated with the programme. This would seem to suggest that if they had been aware of the possibility of their own involvement at this level they might have interpreted participation in this way. However, it appeared that as the only type of involvement they were aware of was attending a parenting group or activity, then this was their predominant interpretation of participation.

5.3.3.2. Motivations for Becoming a 'Passive Participant'

When asked why they had got involved in these support groups the primary motivations of these parents was to respond to the needs of their children.

> "It's good for him to mix with other kids" (Questionnaire interview with resident)

There was also a sense from several of the parents that attending groups and getting involved in activities for the children was all part of being a 'good parent' and providing the best for the children.

> "Well I just think that if they want the best for their kids, then they would come anyway. That's my views anyway. There is a lot more going on that makes my family feel better. I generally think if parents thought like that then they would come anyway. I know some parents just can't wait to get the kids out of the door. I think there should be more parents that do get involved, because there are a lot of kids in {the area} and they haven't got a lot of stuff to do. Especially the smaller ones, they do get bored. I know my little boy 'R', sometimes I don't know what to do with him" (Interview with resident, Phase II).

The parents interviewed were also aware of their own needs and expressed a desire to meet others in the same situation.

> "It was something to do. It's good to get out of the house and to meet other mums" (Questionnaire interview with resident).

One interviewee identified the importance of joining a parent and toddler group as a means to finding out what else was available in the community.

> "Unless you go to a group like this you don't find out about anything, you don't hear anything. I've lived here for two years now and it wasn't until I had my baby that I started finding out what was getting on" (Interview with resident, Phase II).

5.3.3.3. Motivations for Becoming an 'Active Participant'

Interestingly, all those who were more active participants, running groups or getting involved in decision-making, said that they had started off as more passive participants attending parenting groups; many had then developed into group facilitators and eventually become committee members organising group sessions and taking decisions about how to run the group. Those that had taken on facilitation roles within the groups or joined the group's committee discussed their desire to help other parents in the area.

> "I did it so other mums had somewhere to go" (Questionnaire interview with resident).

Others felt that getting more involved with parenting related groups and with other families in the group might help them with their own parenting.

> "I wanted to be involved with other kids for my daughter" (Questionnaire interview with resident).

Others had religious motivations and saw helping out with such groups as a way to improve and develop their own and others' lives.

> "With Jehovah's witness, is all to do with the future and how to live your life" (Questionnaire interview with resident).

One of the residents interviewed was very active in the community and had been involved in the working groups of the regeneration scheme since its inception. For her the motivations for participating and making a considerable commitment were to improve her community, but also a belief that the agencies would not necessarily act in the best interests of the community.

> "I do it to better the community. I've raised my own kids here and feel that if the agencies were involved they wouldn't necessarily do what we want, so I got involved" (Questionnaire interview with resident).

The active participators often expressed a feeling of responsibility for improving their community and communicated a sense of agency and belief in their ability to create change. The resident below was active in establishing a children's 'play and stay' session and demonstrated a clear sense of her own role in improving services for children in the area.

> "I'm not sure, there was one lady that came to the last meeting we had.... But she was very negative, saying, 'nothing is ever done'. It was quite hard to say, 'well that is what we are here for'" (Interview with resident, Phase II).

This same resident also expressed a view, similar to that held by many of the agency staff interviewed, that by establishing these groups they could support others to become more active participants. She felt this would be of benefit to the individuals by helping to build their confidence.

> "There was another girl that didn't come to the last one but came to the first one that was really, really lovely and I think it would have been good for her as she didn't have lots of confidence. She had a baby and I think she is the sort of person that could really benefit from something like that. She seemed really intelligent and capable of doing stuff" (Interview with resident, Phase II).

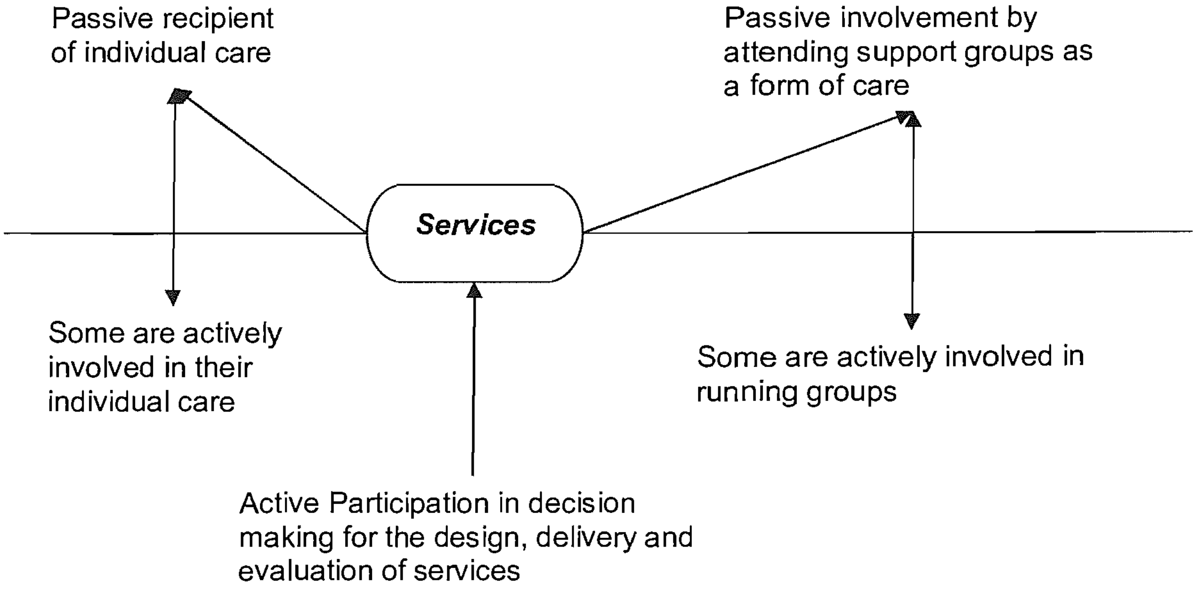
To summarise, the residents interviewed fell into two groups; those that could be said to be 'passive participants' attending groups and activities and those that were more 'active participants' involved in running groups and making decisions about services. The passive participants were motivated to attend groups for the benefit of their own children and to build social support networks with other parents. The active participants were also driven by a desire to better support their own families, but also to improve the situation for other parents and the wider community. An interesting feature of the experience of the more active participants was that many had started their participation journey as passive participants attending parenting groups.

5.4. Interpretations and Motivations: Co-Researchers' Discussion and Reflection

Much of the emphasis during the discussions in the early action research session was on the meanings of participation and how this related to the work of the programme. To help stimulate discussion and reflection, I produced a summary of debates and ideas from the participation literature and shared this with the group (see appendix 4). It was also distributed more widely among the programme and its partners to encourage greater debate about participation (Objective 5). Within the action research group I presented several competing definitions of participation. As a group we were then able to reflect on the differences between these definitions and how they might each be translated into practice. Arnstien's (1969) ladder of participation also proved useful and steered our discussions to reflect on the participatory relationship between the wider regeneration programme and the local community.

As explained in Chapter 4 some of the co-researchers where able to conduct the interviews during Phase 1, this further helped in deepening their understandings of the interpretations and motivations held by others, both agency staff and residents. All the co-researchers were able to discuss the key themes derived from analysis of this phase and this guided our discussion on what participation meant of the programme. In order to clarify the differences in interpretations of participation identified during the reconnaissance phase, I and one or two of the co-researchers involved in the interviews developed the diagram below (Figure 13). The diagram summarises the many ways that agency staff and residents identified for getting involved in the programme and its services. Many of the residents interviewed associated participation with the passive forms of involvement identified above the line while the agency staff focussed on the more active participation identified below the line.

Figure 13: Types of Passive and Active Participation in the Programme



5.4.1. Citizen Control

We were particularly interested to think through Arnstien's (1969) concept of citizen control. While the co-researchers felt that in theory the idea of citizen control was attractive, they identified several constraints to operationalising the concept within their local context. As one co-researcher pointed out, "Citizen control... looks like Utopia!" (Action Research Session 3)

There was concern that the interests of the community were too diverse to be united in some form of citizen control and that inevitably one group would dominate.

> "I find it hard to envisage citizen control; as they'd all end up squabbling among themselves and not agreeing, somebody wants this and somebody wants that and nothing would ever get decided" (Action Research session 3).

In addition to concerns about the homogeneity of the community and the practicalities of citizen control, others in the group discussed the restraining factors of being part of a statutory organisation and that in reality, participation had to be about creating a 'stronger voice' rather than aiming for citizen control.

> "I think the trouble with citizen control is that you're talking about statutory organisations like city council, NHS, like Education, how would you get citizen control when they have budgetary constraints, they have working practices, policies and procedures? I think it's really good to get a stronger voice within that" (Action Research session 3).

Furthermore there was some debate on whether the policy focus on participation within deprived communities was merely adding to the strain facing residents with already complex lives:

> "It struck me that what we're asking for from communities is something that we don't ask of the Mayfair's of this world. They don't have to get involved as they just pay for the services they want. If they don't want to wait on the NHS queue they just pay for them. We don't ask them to have residents groups. What you're asking for is a lot from communities, when they've got so many struggles" (Action Research session 3).

It is interesting to compare the discussions of the action research group with the interpretations of participation given during the interviews conducted with agency representatives and residents during the reconnaissance phase. The findings from this initial phase stimulated the action research group to reflect further on the meanings of participation used in rhetoric and reality by both agencies and residents.

5.4.2. Participation as a Journey

For the action research group the discussion and analysis of both the resident and agency interviews highlighted the gulf between the interpretations of participation. While the agency staff, particularly those working for the regeneration programme, emphasised resident involvement in decision making, for the majority of residents interviewed this was a new concept, they could only be described as passive participants. While these passive participants might attend groups or activities, they did not immediately recognise their role in articulating views or getting more involved in the design and management of groups and services. These findings chimed with the experience, both personal and professional, of many of the co-researchers. Many of the co-researchers had also started by joining a parenting group and then worked their way through managing groups and for the staff co-researchers, this had eventually led to employment within the programme. All the co-researchers who had developed in this way recognised the value of these groups as potentially building the confidence and sense of agency of those that become more involved in their running.

> “If I think about my own experience, you come in as an ordinary member and then you get... find your place within the group and you start to recognise the skills that you have already got. You become a part of the group and you can take on more responsibility, but that is a growing process. Some people actually quit as that can be a very slow process and you may have to be along side someone to help them to get to that point. But doesn’t mean that because they can’t do it when they walk through the door that they can’t do it in the future.” (Co-researcher, Action Research session 3)

This idea of participation as a journey to develop a stronger sense of agency was central to the discussion of the action-research group and to the work of the programme. There was agreement that for parents there is a need to support them through a journey of empowerment, starting with attending parent support or play groups as the first step on the participation ladder and then working towards greater involvement in decision making, voicing concerns and views. However, for the co-researchers the idea of citizen control was felt to be unattainable within the bureaucratic limitations of statutory organisations and the un-cohesive and under-confident community.

5.4.3. Motivations for Participation

Phase 1 of the project and the early action research sessions looked beyond interpretations of participation to explore why both agencies and residents wanted, or did not want participation. This helped the co-researchers think through their own motivations for encouraging participation within the programme.

For the co-researchers, exploring these motivations highlighted many similarities with their own understanding of the reasons for encouraging participation. Before embarking on the reconnaissance phase the group discussed their own motivations for encouraging participation within the programme. They identified many benefits to the individual getting involved as can be seen below. The benefits they identified for the programme show the value they place on participation.

The reasons for encouraging participation within the Programme as Identified by the Action Research Group

Benefits to programme:

- Project staff learn new things
- Pulls the community together
- To ascertain needs
- Making a contribution to decision making

Benefits to individual:

- Reduces isolation
- Joining in
- Taking part
- Meeting new people
- Express your opinion
- Have fun
- Have a say in matters
- Learn more
- Build self esteem and start to recognise your own skills
- Develop transferable skills

It is interesting to note that in this brainstorming session there was no mention of the benefit of participation and feedback to develop and improve the services on an ongoing basis. This may have been an oversight as clearly developing feedback mechanisms became a key part of the strategies that were used in subsequent action – research cycles.

Different co-researchers had slightly different motivations for participation. For some, particularly those that lived or had lived in regeneration area or similar, there was real motivation for increasing parents' confidence and self-esteem and a belief that getting more involved, particularly joining groups could help someone in this way. For others there was a recognition of the programmes' obligation to encourage participation which was also clearly a motivational force.

> "I think that partly we are doing it because {the regeneration scheme} want us to do it" (Co-researcher Individual interview).

There was also a feeling that it was the right of residents to have a say over the programme as it had clearly been established to help them and that, without their input, the programme might not meet their needs.

> "They have got to be involved because they are going to be the service users! It's about making it applicable to what they need, so that it's something that they want. We'll see one gap and they'll see another, we'll fill our gap and the residents will just say why don't you do anything for us" (Action Research Session 7).

It became clear through the group's reflection on the findings of the reconnaissance study and through the discussion of the meanings and motivations for participation that the co-researchers appreciation of their contextual environment and for many, their own experiences guided their understanding of what they meant by participation and why they wanted it within the programme. Central to this was the idea of the 'journey of participation'; that although an individual might begin with a fairly limited form of participation, for example joining a parenting group or filling in a feedback form, that this could at least help the individual feel that they were valued and that views were considered important by the programme. The co-researchers felt that this could potentially be the first step to becoming more engaged with the work of the programme and help the individual to progress up the participation ladder building their confidence along the way.

Summary

To summarise, the agency representatives interviewed saw participation as a broad spectrum, however there were differing opinions as to the nature of either end of the spectrum. For some the most participatory end of the spectrum was having some influence over existing programmes, others went further expressing an aspiration that participants should be 'in the driving seat' determine the type of programmes delivered. For the majority of residents interviewed the main interpretation of participation was passively attending groups or activities. Only those already active in the community understood participation as a way of engaging with decisions about services within their community.

The findings show that agency staff were motivated to encourage participation as they felt it would benefit the services they provide in terms of increased relevance to local needs, improved chances of sustainability, as a means of communicating with the community, but also as a policy imperative driven by the political agenda. There was little evidence that staff felt participation led to greater economic efficiency in the short term at least. The agency representatives were also motivated by a belief that greater participation could benefit the lives of those participating, specifically by building skills and knowledge, raising self-esteem, strengthening social networks and helping individuals to take responsibility for their own health.

The residents interviewed also identified benefits in terms of widening their social networks and support, particularly among young mothers going through similar experiences. For many their primary motivation was to benefit their children through contact with others. Those who were more actively participating were motivated by a desire to improve not only their own lives and that of their families, but also the lives of those in the wider community, something that they felt should not be left to the agencies alone.

For the co-researchers this underlined the importance of seeing participation as a journey, often starting with quite passive attendance at groups but then growing into more active participation. For the co-researchers who lived or had lived in the area this idea was particularly important, primarily because they had also gone through their own 'journeys of participation' to reach their current level of confidence and involvement.

Chapter 6: Findings III: Establishing a Participation System

This chapter begins with an explanation of the co-researchers' reasoning behind the action elements of the study. This is followed by a presentation of the co-researchers' decision to articulate their approach as a 'participation system'; each component of the system is then defined. The following sections take each of the six components in turn and explore them in more detail. For each component this is done by firstly explaining the approaches used by the co-researchers, secondly, by discussing the experiences of implementing these approaches in practice whilst drawing on data from the observation stages of the action research cycles and finally, by presenting any plans for improved implementation given by the co-researchers in the final feedback session. The final section of the chapter presents the findings from the techniques used to measure participation. The co-researchers' reflection of the value of these techniques is also presented.

6.1. Moving into Action

The reconnaissance phase provided the co-researchers with perspectives from both agency staff and community members on the interpretations of and motivations for participation. It also identified constraints facing community members in participating in the existing NDC structures. As described in Chapter 4, the co-researchers were involved to some extent in the analysis of the findings from reconnaissance phase and this helped them to appreciate the different perspectives and issues that arose. After analysis by the co-researchers, the findings from the reconnaissance study were written up in an accessible format for programme staff within NDC and the health trusts. This six page document is entitled 'Participation Brief II' and can be found in Appendix 5. the reconnaissance phase findings are also drawn on throughout this chapter in order to illustrate the constraints to participation faced by the community.

The co-researchers were able to combine the findings of the reconnaissance phase with their own experiential knowledge gained from living or working (or a combination of both) in the area. This helped us develop some initial action plans to guide our action-research cycles. A list of the 3 key action objective is given in Chapter 4, figure 8. The action plans focused on the gaps in attempts to encourage participation within the programme. So, for example the co-researchers were well aware, from the reconnaissance phase and their own experience, of the lack of confidence that many community members, especially young parents, had in joining groups. An action for the co-researchers could have been to try providing individual support to community members by accompanying them to group sessions. However, within the programme there were eight locality family workers who had as part of their remit the task of supporting their clients to attend groups. Hence, instead of implementing this action ourselves, we decided to rely on the existing work of the family workers, but ensure that we monitored the success of this support as a strategy for encouraging participation. This was done through the review of the locality family worker service conducted during the action-research cycles.

The actions, therefore, focused on the areas where we felt there were gaps in existing attempts at encouraging participation. The initial emphasis of the group was on identifying ways to increase awareness in the community of ways to give their views and to participate more extensively. The achievability of the actions was also carefully considered. This led to an emphasis on developing ways of communicating with clients and community members, facilitating the feedback of their views on the key services coordinated through the programme, i.e. health visiting, midwifery and the locality family workers. Ideas on how to increase participation in the decision-making structures of the programme required much in-depth discussion among the group and as will be explained below, took longer to emerge.

6.2. The Need for a System

Over the period of the study, the action research group explored, debated and discussed ideas about participation with the central aim of improving the levels and quality of participation within the programme. At the beginning of the year there was no clear idea of the most appropriate techniques to use. The beauty of using the action research cycles was that as co-researchers we could try out different ideas and approaches. Throughout the study period it became increasingly clear that participation techniques, such as feedback events or forms, were only one part of the response. To develop a more participatory programme attention needed to be paid to communication with clients and the wider community, even those who would not normally get involved and crucially that their views are heard and responded to by decision makers.

This last issue was a particular concern for the co-researchers and many of the action research sessions focused on how to ensure that client and community members' views actually influenced the development of services. The co-researchers felt that much of the consultation that had taken place to-date was disassociated from the decisions that were taken throughout the regeneration programme. There was real concern among the co-researchers that merely asking resident's views without being able to respond or feed the points raised to decision-makers could be counterproductive.

> "So we need to get the managers on board to say who opens the suggestion box, who answers that, how do we get back to people? If we haven't got answers then it won't work. It's all very well having a scribble board, but if they raise queries we need to be able to answer them" (Action Research Session 6).

It became clear throughout the cycles that without effective means of communicating with clients and the wider community and without ways of ensuring their views were responded to by decision-makers; there was little point in establishing opportunities for participation. Through the analysis process I was able to piece together the elements of the process that we had identified as a group through our reflections and discussions. I then drew these elements together and presented them back to the group as a coherent system. As a group, all the co-researchers were in agreement that participation must be seen as a *system*, where all components of the system must be functioning. If the focus is on developing just one component of the system to the determent of other components then the system will fail and participation within the programme is likely to be minimal and unsustainable.

6.3. The Components of the System

The system is depicted in Figure 14 below. The components of the system are:

1. **Entry Point**: The communication and support needed to inform and encourage clients and the community to participate in the programme

2. **Modes of Participation**: Forums, tools and techniques for clients and the wider community to give their feedback on services, express their views about family support in the area and influence the design and delivery of services

3. **Collation of Feedback and Views**: Programme staff develop a regular mechanism for analysing and collating feedback and views. Where clients and community members are directly participating in decision-making within the programme this component is not needed.

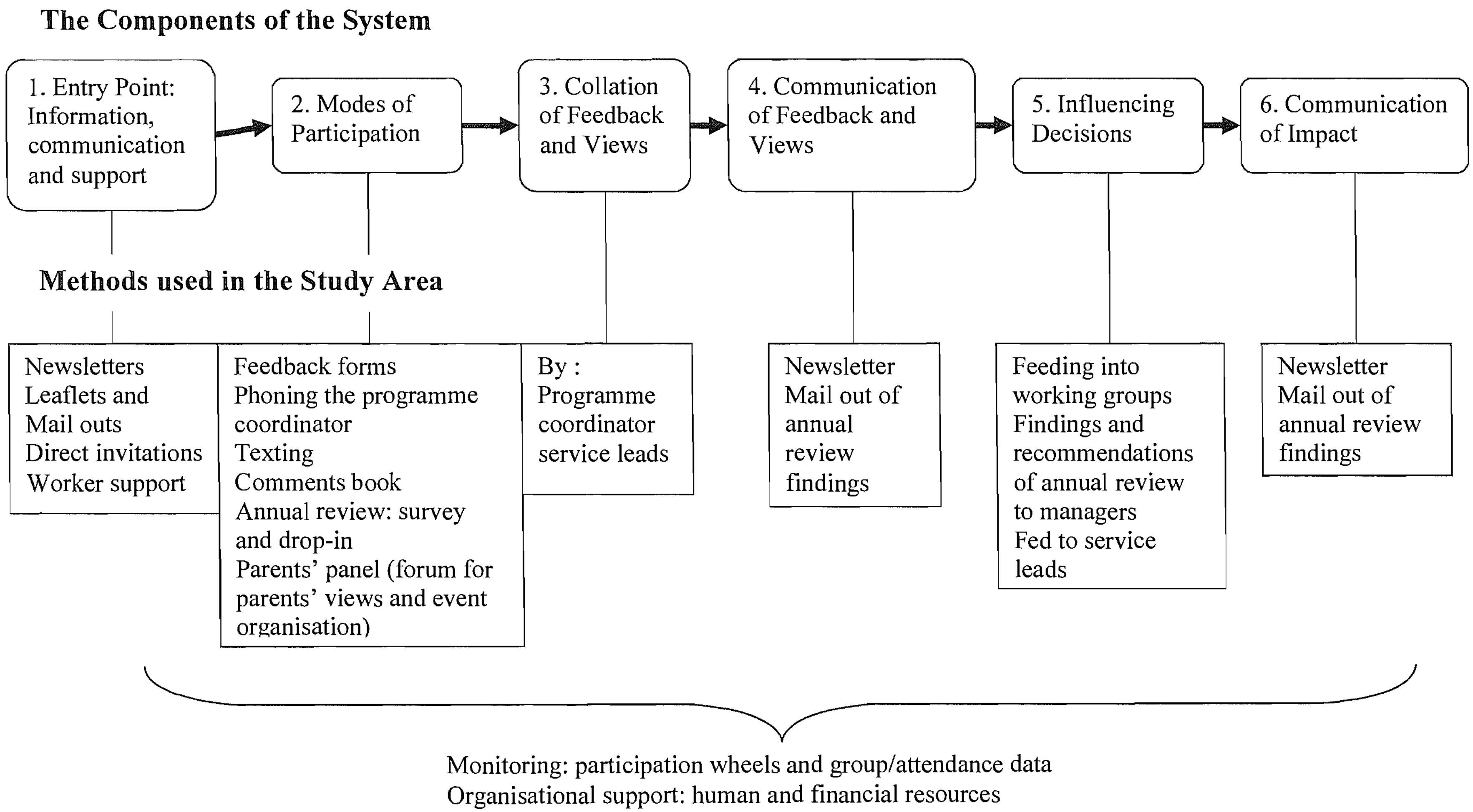
4. **Communication of Feedback and Views**: The collated feedback and views are presented back to clients and the community so they are aware of the opinions of others.

5. **Influencing Decision-Makers**: The feedback and views are articulated to those responsible for making decisions about the programme, either directly by clients and the community or indirectly by programme staff.

6. **Communication of Impact**: The response of decision-makers is communicated back to clients and the wider community; this may be in terms of changes made to the service or explanations for why the requested changes can not be made.

The group felt that in different situations different component of the system may dominate or be of less importance, for example in some situations it was felt that component 4 – communication of feedback and views, could be omitted if there was a speedy response from decision-makers thus allowing views and their eventual impact to be communicated simultaneously. Furthermore, it was felt that when the programme had progressed to greater levels of participation, clients and community members would be able to be part of programme decision-making processes thus negating the need for programme staff to collate and represent views on the behalf of clients and community members (component 3); although this could still be needed in order to reach the wider population and specific isolated groups.

Figure 14: The Participation System



6.3.1. Entry Point: Information, Communication and Support

The first constraint facing the programme was succinctly explained by one of the residents interviewed during the reconnaissance phase.

> "I didn't know these groups existed. No-one ever told me about it" (Questionnaire interview with resident, Reconnaissance Phase).

Discussions among the co-researchers highlighted how the regeneration scheme itself had not been effective in communicating with residents, particularly letting them know about services or events.

> CR[3]: "but how do you get them there in the first place, because I think this is the bit that NDC doesn't do, if someone gets the right piece of information its just pot-luck. I got something through on a city wide thing and well, you need that information at the right time. If you get it, I don't think the NDC system allows us to do that" (Action Research Session 3).

As a newly established programme much work was needed to advertise the groups and services on offer. Clearly this was important for meeting all the programme's goals and targets, however, given the action research group's concept of participation as a journey; increasing awareness about the activities of the programme was seen as a way of establishing contact with parents. The locality family workers' role in providing one-to-one support to parents gave the co-researchers an ideal opportunity for encouraging more isolated parents to attend various groups and sessions. The co-researchers felt that this process of support and encouragement could potentially lead to more meaningful participation. Hence the communication, information and support described here is both for the actual services provided by the programme as well as ways for residents to provide feedback on services and participate in aspects of programme design and development.

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[3] CR: Co-researcher. Where the Co-researchers are engaged in dialogue they are numbered to show who is speaking. However, these numbers are not consistent across quotations, i.e. CR 4 in one quotation will not necessarily be the same as CR4 in another quotation. This has been done to maintain anonymity of the co-researchers.

6.3.1.1. Newsletters

The programme made use of the New Deal for Communities' main quarterly newsletter as well as a smaller newsletter focusing only on health. The main NDC newsletter is delivered with the free local paper and should therefore reach every resident in the area. The health newsletter is distributed every three or four months, 4,000 copies are printed and delivered to every home in the regeneration area. The programme has included articles on their key services and updates on special events as well as ways to feedback and summaries of clients' views on the service. The programme coordinator did have some responses from the communications in the newsletters, particularly around attending special events.

When asked during the final observation stage of Phase II whether they had received either of these newsletters, there was a mixed response. Two out of the six residents interviewed had never seen a copy of the NDC newsletter and only one had seen the health newsletter. Two of those interviewed had read about family support in the NDC newsletter, but in general the residents admitted that if they did receive the newsletter they rarely read it in any detail.

> Co-researcher interviewer: "Did you ever receive anything like that?" {Holds up NDC Newsletter}
> "I'm not being funny, but when I got one of those before, I chucked it away 'cause I didn't know what it was. It was only because last time I was bored, so I thought 'well actually...' and had a look. But they don't come out very often."
> (Resident interview Phase II)

6.3.1.2 Leaflet Distribution

The most common method for communicating with residents used by the programme was to design and print out leaflets detailing available services and special events. The programme decided to use bright orange paper for these leaflets in the hope that they would be more visible and become automatically associated with the programme's services. By the end of phase II of the action research project the programme had distributed leaflets detailing family support services and ways to participate to local schools, the doctor's, midwives' and health visitors' clinics and sessions, several other local projects as well as the housing office to include in a pack for new tenants. The locality family workers were also able to distribute many of the leaflets to their clients.

However, the programme staff continually expressed concern about the lack of response to the leaflets. This was particularly obvious after sending all the family worker clients a leaflet with details of the 'parent's panel' (see below). The mail out solicited not one response.

However, the residents interviewed during the final observations of phase II consistently commented on the lack of information on available services and support for families. Although one resident was able to identify one of the Programme's groups, known as 'family point', as providing information and giving out leaflets.

> Resident: "The only one that gives out leaflets is the parents club on a Monday at the church. They have leaflets there."
> Co-researcher interviewer: "That's 'family point' isn't it?"
> Resident: "Yes that's the word I was looking for. They have got lots of leaflets down there. They are pretty good for letting you know what is on" (Resident interview Phase II).

For one of the residents interviewed, the only way to find out about services and support was by taking the initiative to join a toddler group.

> Resident: "When I first had the baby I asked the midwife what is there to do here and she said, well not much really. And it wasn't until I had my baby boy and I came up here and then from here I found out what was on" (Resident interview Phase II).

While few residents had seen the leaflets distributed, it was interesting to note that in the hallway outside one of the toddler groups where three residents were interviewed, there were several piles of the Programme's leaflets. However, the residents had no knowledge that they were there.

There were occasions throughout the study period that leaflets did solicit a response, even if it was a minimal one. For example during the annual review of the locality family worker service, leaflets were sent to all clients inviting them to fill in a questionnaire and to attend drop-in sessions. As a result of this mail out 5 clients did attend the drop-in sessions to give their views. This may have been because a prize draw for a supermarket voucher was offered to those who did attend and more importantly because the locality family workers were able to explain the purpose of the review and emphasise to the clients how their views were valued.

Throughout the study the co-researchers were very aware that for the parents targeted by the programme the written word, both through the newsletters and leaflets, was not the most effective means of communication. Several reasons for this were given, firstly that literacy levels in the community are low and secondly that with the arrival of the regeneration programme there was concern that residents have become overloaded with newsletters and information and were unlikely to read any of it thoroughly. The group also felt that with the low levels of confidence and self-esteem many of the parents, particularly the younger ones, were unlikely to take the step of coming to a group on their own based on an advert or article in a newsletter. These concerns held by the action-research group were reiterated by several of the residents involved in community work in the area. The quotation below is from a young mother who has worked to establish a toddler group in the area.

> "A lot of it is, I think people need to know that they are just as good as anyone else, they might live in a council estate, but that is where the difference ends and people just need confidence in themselves and need to know that they are capable of doing stuff and of changing other people's lives and helping other people. I don't know what the answer is, but I think it is more on a personal level; each person would need to be told. If someone just read on a leaflet that they are capable of doing something of changing things, then they are not going to believe that is personal to them. People need to.. it's a long process" (Interview with Resident, Phase II).

During the final action-research session, the co-researchers discussed the lack of impact of their leaflets and agreed that where possible available workers should make a point of handing leaflets personally to clients and explaining the service or participation offered. The limited success of the locality family workers in encouraging their clients to come to the annual review drop-in sessions showed how this strategy of combining leaflets with explanations and encouragement could be a more effective way of communicating with clients and encouraging their participation.

6.3.1.3 Direct Invitation

Members of the action research group had continually expressed concern that leaflets and newsletters would not be sufficient to inform and encourage residents to get involved in activities or to participate in the programme. The group decided instead to invite clients or community members, either by word of mouth or by telephoning, directly to attend groups or sessions.

This strategy was used when setting up the parent's panel, a forum for parents to get involved in organising activities for children in the area and to give their views on how family support services in the area should be developed. The experience of the parent's panel is explored in more depth in section 6.3.2.7, however this strategy of phoning or talking directly to clients and the community was effective in that five parents did agree to join the panel. However, the key consideration for the group was *who* should be invited to join the panel.

There was some debate among the co-researchers of who should be invited in this way and the appropriateness of this strategy as it was likely to exclude the more socially isolated who were least likely to have the confidence to get involved. However, given the client base of the programme, several of the co-researchers felt that for many getting involved on almost any level would be challenging given the complexities of their lives:

> "Yeah and I agree with you, its better for family workers to identify people who feel they can offer something and are in a place where they feel they can offer something. As someone might like to do it in their dreams, but just has not got the head space to do it because there are too many things going on for them" (Action Research Session 15).

Several of the co-researchers, including myself, were keen that some clients who were not already active in the community should also be invited. However, this idea was met with some scepticism by others in the group as demonstrated in the following interaction during one of the action research sessions:

> CR1: "I think it really is just the more motivated that would be capable of doing it. The less motivated will not have the sustainability to do it.

> F/CR[4]: if there are a few though – as it is a great way of building people, if you can get a mix of some who are really strong and some that you can help along in the process.
> CR2: yes its building up confidence isn't it
> CR1: yes but you couldn't have too many as they would otherwise drag the group down. Or they wouldn't come" (Action Research Session 15).

During the final observations of phase II, one of the residents who had attended the parents' panel expressed concern that this strategy had meant that only those already active in the community had joined the parents' panel and that this had stopped those not used to voicing their opinions from attending. Moreover, that if those not used to participating had come along, they might not have contributed due to the dominance of the already active participants.

> "I think the idea of it was pretty good, but it was just that everyone that was involved in it was already doing something quite big in the community and it was targeted at.. well I expected there to be lots of other people, but we were the only ones that turned up.... I think some people let others come up with ideas and just sit there with their arms folded and I think it would be good to have everyone. I could have probably dragged some friends along. But they would have been the sort of people that come to my toddler group and are already involved" (Interview with Resident Phase II).

So whilst the idea of directly inviting clients and the community to join groups or attend session was successful, the question of who should be invited is crucial. Determining who attends the group influences its dynamic but also, as we shall see in section 6.3.2.7, ultimately to its sustainability.

6.3.1.4 Worker Support

As mentioned above, a key aspect of the programme was the locality family worker service to support vulnerable parents in the area. These workers were a valuable resource as they could provide the encouragement and information needed to help their clients attend groups and sessions and become more active in the community. Given that the co-researchers identified how participation was often a journey, starting by attending a group as a passive participant and with the right encouragement,

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[4] F/CR: This denotes the facilitator/co-researcher… the author.

becoming more active over time, this idea that the family workers could 'hand-hold' a parent through the process was very attractive. As one co-researcher explains,

> "If we spend time with that person then you can grow that person into a role and give them the training to take on that responsibility, but that takes time and shoving a leaflet in front of someone isn't going to be the be-all and end-all of everything, getting that person to walk across the door." (Action Research Session 3)

The questionnaires used in the annual review assessed how effective this strategy of locality family workers' support was in encouraging clients to attend groups. 92% of those that returned the questionnaire said that their family worker had told them about services or groups of interest to them. Of this 92%, 52% had actually gone along to the recommended groups or services. Many of these were accompanied to their first group sessions by their family worker and identified this as a positive experience during the qualitative elements of the review. The review did not explore in any detail how effective this strategy was for sustaining the client's involvement in these groups. Several of the co-researchers expressed concern that when the family workers stopped accompanying their clients they were unlikely to continue to attend the group. However, it would appear that this strategy was effective in encouraging the locality family worker clients – often the most isolated in the community – to take the first step on the participation journey.

To summarise, effective communication is needed to provide an entry point for programme clients and the wider community to participate at any level. The most commonly used means of communication were leaflets and newsletters, these proved to be of limited effectiveness only stimulating very limited levels of participation. When coupled with direct support and encouragement from programme workers there was a much better success rate in facilitating participation, although sustaining this participation may still be a challenge. Directly inviting community members to join groups and activities was also successful, however, the key question of who is invited to join has significant implications for participation within the programme.

6.3.2. Modes of Participation: Tools and Techniques

Within the action research group we spent much time discussing how to make it easy for all the programme's clients and the wider community to give feedback and to start to get more involved in the design of the service. The interviews and questionnaires during the reconnaissance study coupled with the experience of the co-researchers highlighted different levels of confidence, interest and time available to residents to engage with the service (see appendix 5 for reconnaissance phase findings).

By offering a number of different ways for residents to give their feedback or participate within the design of the service, the group hoped to be able to offer a greater range of residents the possibility of participating in some way. The modes of participation described below are presented in the order in which they were introduced and reflected on by the action research group.

6.3.2.1 Feedback Events

As part of the wider regeneration scheme, several community events were organised throughout the course of the year. The first of these was a health promotion event which involved stalls with information on many health related services within the community. The programme organised activities for children as well as providing information about their services and local groups.

For the action research group this was an ideal opportunity to start to engage with parents. We wanted to have some idea of how parents felt about service provision for children of different age groups. Deciding that a creative approach might be the most effective we designed cut out figures of children of the different age groups served by the programme. Whilst the children were involved in the activities we were able to ask parents for their views.

Originally the idea had been to give parents post-it notes to write their points and stick these to the relevant cut-out figure. However, it soon became clear that some parents were uncomfortable writing their comments directly, even though there was no link between their name and their comment there was some concern that this would be discovered or that to write an overly negative comment about a particular worker or service was not the right thing to do. So, while some were happy to write their comments directly, others preferred to talk in more detail and in confidence with a worker and then allow the worker to summarise the issue to maintain anonymity. We were keen to find a core group of residents that would be interested to get more involved in the programme, so a box was available for those interested to give their names and address.

In all, 29 parents gave their feedback on the services available. The comments ranged from broad suggestions about improvements to the local area, to specific comments about the health visiting or midwifery services. These were then reviewed in the next session of the action-research group. During this reflective session, the co-researchers expressed several concerns and opinions.

There was some concern that we had fallen into the common trap of asking people for a wish-list of improvements. This was of particular concern to the most experienced member of the group and was a common theme in her reservations towards soliciting feedback:

> "My reservations are, and you probably won't be surprised to hear, are that we are going to get people asking for things that we can't provide; because I think that for workers that can be demoralising, when people ask for things that you have no control over providing" (Individual interview with co-researcher).

Further frustrations were voiced at finding out that some parents may have been dissatisfied with the service provided without raising a complaint.

> "The comment about the health visitor, you would think if they are not satisfied, well why don't they tell you they are not satisfied? I mean nobody is a mind-reader." (Action Research Session 6)

There was some discussion among the group as to how the programme or wider services should respond to some of the issues raised in the feedback. There was a general perception that individuals themselves should take responsibility for their own actions and that this idea should be communicated to residents.

> "A lot of these things could be done by people themselves, like the people that walk dogs, they should pick up the dog poo!....For the newsletter we could put an article together that covers these points. We could actually say that {the regeneration area} is your community, and we can all play our part by not

> dropping rubbish and encouraging children not to drop their sweet papers and things like that" (Action Research Session 6).

Using this simple mode of participation was quick and easy and did help the programme staff to engage with their clients and the wider community. However, it also raised a number of issues about participation, particularly the need to be clear of the purpose of the exercise. The co-researchers felt that in future we should avoiding asking broad questions that might solicit a 'wish-list' thus raising community members' expectations.

6.3.2.2 Telephoning the Programme Coordinator

A further strategy tried by the group was to reformat appointment cards used by the locality family worker clients to include the telephone number of the programme coordinator for clients to call with any complaints, suggestions or even compliments about the service they had received. The number was also included on all leaflets and information about the service.

To get some indication of how clients felt about this feedback option, the clients interviewed during the final observation stages of phase II were asked whether they were aware of this option and whether they had, or would consider using it. Of the two family worker clients interviewed, one had misplaced her card, but still knew the office number and the other had the card. They both said they would be happy to call the programme coordinator to discuss any problems.

> "I'd have no problems in phoning up {the programme coordinator} and talking about anything if I've got any problem" (Resident interview, Phase II).

However, this client went on to say that when she had had concerns about her family worker she had actually gone to a support worker within the school as a first point of contact. The support worker had then arranged a conference with the programme coordinator to address the problem. The client felt that this had solved the problem. The other client interviewed discussed some aspects of her relationship with her family worker that she felt could be improved, however although she was very aware of the option of phoning the programme, she had not done so. Hence, while in theory the availability of the option to phone the programme directly to feedback views or discuss concerns was accepted by those interviewed, when actually confronted with a problem the option of discussing it through a more neutral and trusted third party or not addressing the problem were more common responses among those interviewed.

6.3.2.3. Texting

The group were very conscious that for many attending events or meetings, filling in forms or phoning the programme directly would not be the most accessible or appropriate means of expressing either concerns about individual support or bringing broader complaints or suggestions about the programme. As many of the parents in the regeneration area are young, the idea of using a form of communication more familiar to them was very appealing. The programme was able to link with the local Church of England family worker to establish a texting service for residents to feedback any comments or suggestions relating to family services in the area. In conjunction with the church, the programme advertised the texting number through a leaflet sent to all the locality family worker clients of the programme and distributed at local clinics, groups and special events. The church's family worker took responsibility for reading the texts, he explains below how he dealt with text messages after a family event held in the community.

> "If they want a reply they don't withhold their number and then I can text them back. For example one said "it was brilliant, but that we need more races", so I texted back and said that the committee would be meeting and I would forward the comment to them" (Church family worker in action-research Session 12).

The family worker was invited along to the action research group to feedback his experiences with the texting service. This gave the co-researchers a chance to reflect on what worked well with the texting service and what they could do to improve it. The main concern was that while residents – both parents and teenagers - were making use of the service after key events they were not using the service to give feedback about the on-going work of the programme, particularly their interaction with the locality family workers, health visitors or midwives. The service was used the most after a large event, for example 15 texts were received after a disco held for young teenagers and after one of the health fairs held in the community a further 15 texts were received. The texts received were both positive and negative, often with ideas on how to improve the event itself. During the action research session, the group were keen to advertise the texting service more widely to try and encourage greater use.

The action research group felt working with the church was a good way of developing partnerships with others working with families in the area. There was also some concern about the future of the Programme and how sustainable its activities would be in the long term. There was a feeling that the church would still be around after the regeneration programme had ended and thus building links now was a valuable thing to do. Furthermore, as the texting service is clearly distinct from the programme, the co-researchers felt clients would be more likely to raise issues that they might not wish to raise directly with the programme staff.

During the observation stage at the end of Phase II the residents interviewed were asked if they were aware of the texting service. None of those interviewed had heard of the service. However they were all keen to emphasise that it was a good idea, particularly as it presented a way of giving feedback whilst maintaining anonymity.

> "Yeah, because if you are worried about something and you don't know how to approach someone then obviously texting is going to be better because they don't know who you are" (Resident interview Phase II).

One or two of the co-researchers, including myself, were concerned that the link with the church might potentially deter some residents from using the service. For the residents interviewed in Phase II this was not seen as problematic and the Church's family worker was clearly valued in the community. However, it must be noted that none of the residents interviewed were of other faiths, so there is no way of knowing whether those of other religious beliefs would feel uncomfortable with the connection to the Church of England.

> "It wouldn't bother me, as long as it gets sorted at the end of the day. He is quite well known too, he goes up the school and does assemblies. This year we took the kids to the Easter egg hunt, and they really enjoyed it and that was {the Church family worker} that organised that" (Resident interview Phase II).

One resident felt the idea had potential beyond a feedback service, as a way of accessing information about parenting.

> "Sometimes you want to ask really silly questions, so it would be good to have someway of doing that by the texting service" (Resident interview Phase II).

While the texting service clearly has great potential within the community, as yet it has a very low uptake. The observations at the end of phase II would indicate that residents, particularly parents, are not aware of the service and have therefore not started to make use of it. Once again this points to the problems of communication and informing residents about the available services and opportunities for participation.

6.3.2.4. Comments book

The co-researchers felt it would be helpful to see what other projects in the region were doing to connect with their clients, so myself and one other co-researcher visited a local SureStart project. One simple way the project had developed to capture clients' comments was a book where staff could write complaints, compliments and suggestions. The co-researchers were keen to trial this within the programme. The book was used predominantly by the programme coordinator to note down feedback, particularly as it came up from other staff during team meetings.

> "Well they've come up from the staff meetings, so I've got something about someone receiving a thank you card from someone acknowledging their shaky start; a telephone contact thanking someone for all their hard work cleaning up someone's bedroom; discussion with a client about change of worker, as they want to wait for the original worker to return from sick as she found the other worker unhelpful, so that's a negative one. Some had a Christmas card from a client thanking her for support and letting her know that the daughter is still doing well. And then one who had observed a family worker working with a toddler and was impressed by the way she worked with the young mum to recognise appropriate behaviour and encourage play" (Action Research Session 12).

However, some concern was expressed by one of the co-researchers during an individual interview that the locality family workers might not want to raise negative comments with the programme coordinator.

> "The worker wouldn't want to put her job at risk by putting things in the comment book" (Co-researcher Individual interview).

By the end of phase II of the study, the comments book had not been well utilised. In fact as of July 2005, the last comment entered was five months previously in February

2005. All the comments had been written in by the programme coordinator. The majority of comments were positive points and 'thank you' messages from family worker clients. The co-ordinator felt that there was still some value in continuing to use the book as the comments within it could be included in future reports and programme proposals.

6.3.2.5 Annual Review

As described in Chapter 4 (Findings I) the annual review of the locality family worker service was used as a means to find out more about clients' knowledge on how to give feedback on the service. As part of the review, questionnaires were sent to all the locality family worker clients, and almost half of these (45%) were filled in and returned. In response to the question concerning knowledge of feedback mechanisms, only 40% of respondents knew how to make a complaint or give a compliment about the service. This was important information for the action research group as although they had established the texting service and used key events to get feedback, 60% of the clients of the clients were clearly unaware of these attempts.

The drop-in sessions that also formed part of the review reinforced this finding that few residents were aware of ways of giving their views. Moreover, many of the residents in the drop-in sessions appeared not to have considered the possibility of doing this. This triggered discussion among the co-researchers and an agreement to mention ways of feeding back during the introductory session with each new client. The interviews in the final observation phase showed that clients had indeed become aware of ways to do this.

The annual review not only provided the action research group with information on how well parts of our participation system were working, but also provided a source for reflection on how to encourage clients' feedback. As explained in Chapter 4 the questionnaire received a good response rate. Thus the co-researchers felt that this was an effective way getting client's feedback. However, on analysing the findings from the questionnaire, several of the co-researchers expressed frustration at not having asked different questions and not being able to find out what lay behind some of the answers. Furthermore we discussed the possibility that those with literacy problems or who were disengaged would be unlikely to fill in a questionnaire. This helped the co-researchers see that there were limitations to the use of questionnaires and could not be used as the only mode for hearing client's views.

While only five clients attended the drop-in sessions, they did provide a forum for more detailed discussion about their views of the service. It also allowed issues to emerge from the clients that had been overlooked in the design of the survey. For example the clients in the drop-in sessions expressed frustration with the office systems for contacting their locality family worker. If the survey had been the only method used then these issues might well have remained unidentified by programme staff.

The co-researchers felt that they had learnt a lot about how best to organise similar sessions to engage with clients in the future. The diagrams below shows the co-researchers' reflection on what worked well and what didn't work so well, and why, during the drop-in sessions.

Figure 15: Co-Researchers' Reflections of What Worked Well During the Feedback Drop-in Sessions

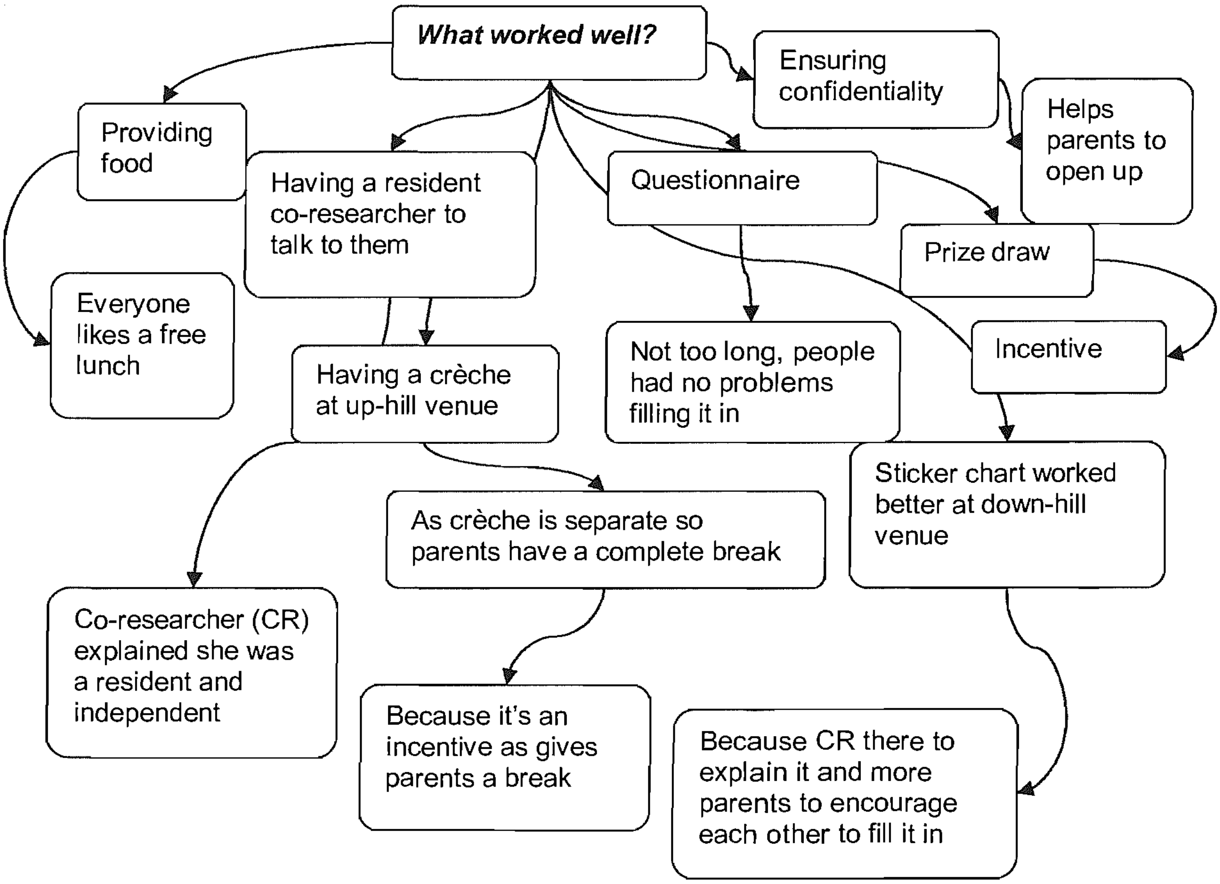
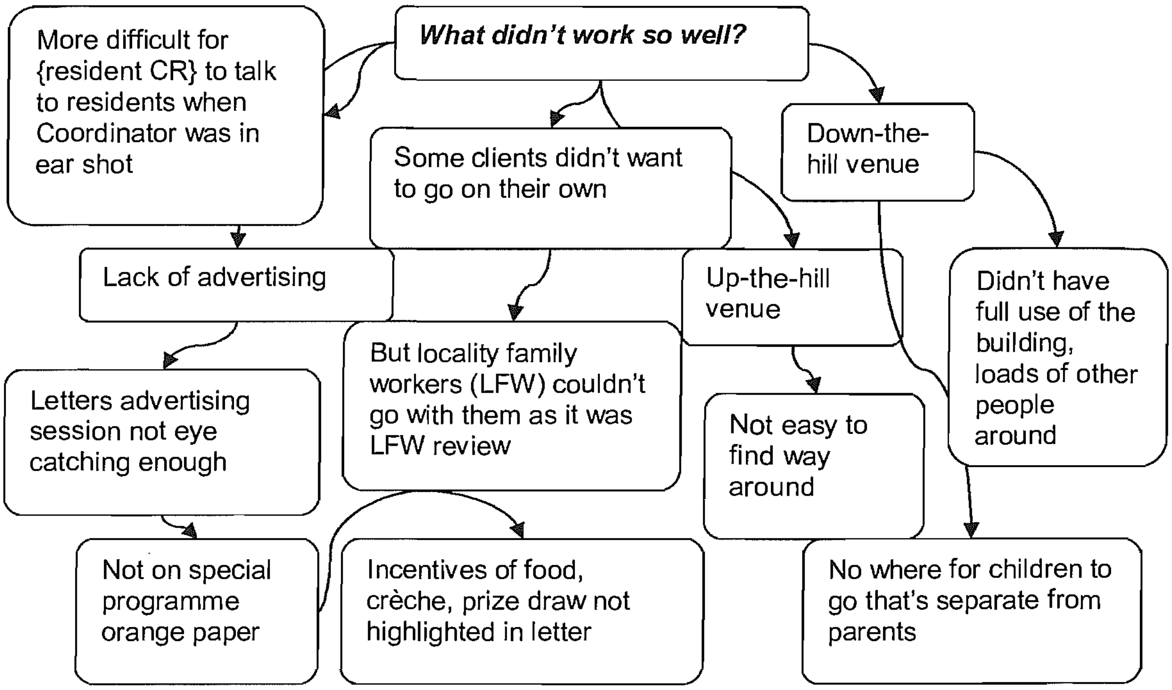


Figure 16: Co-Researchers' Reflections of What did not Work Well During the Feedback Drop-in Sessions



During the co-researchers' discussions on how to conduct these reviews in the future many were keen to have a client-led review of the service with clients designing, conducting and analysing the review. This was a very attractive idea, however the co-researchers felt that until a core group of clients were more involved in the service this would not be possible. These discussions among the group did however, spark ideas for the formation of a 'Parent's Panel' (see below).

6.3.2.6 Feedback forms

Conscious that there were still only limited ways for clients to give their views on the service, the co-researchers decided to develop feedback forms for each of the key services of the programme, i.e. health visiting, midwifery and the locality family worker service. The group's reflection on the use of questionnaires in the locality family worker review highlighted the difficulties clients experienced in writing responses to open-ended questions. There were many more responses to the tick-box style questions than those that required writing. In light of this the group felt that while feedback forms could be beneficial, for clients to actually fill them in they would need to have just a few simple questions with 'yes' or 'no' answers. There was some debate about needing to keep some form of open ended question for suggestions and eventually both were included. The form was then adapted for use by the health visiting service and by the midwives in their baby group sessions.

By the end of phase II of the study each of the aspects of the programme had adapted the use of feedback forms to fit the needs of their service. For the locality family worker service the forms were given to the clients at the end of their time with a worker, these could then be filled in and returned anonymously to the coordinator. The health visitors considered using the forms in a similar way during their home-visits, however this approach was felt not to be successful, as the health visitor explains.

> "But we thought that would work out ok, trying to do it at people's homes. I just went to one and tried to do it, but to try and get them to focus. Like this lady she is a typical social services case and we are watching her to see how she is getting on and they tend to flit a lot from subject to subject" (Health Visitor interview, Phase II).

Instead the health visitors decided to put the forms out during their clinic sessions and actively hand them out every three months. In this way they hope not to overburden parents with constant requests for feedback. The health visitors received 7 responses to their first distribution of their feedback forms. The majority of the comments they received were positive, however they did also get helpful feedback that the clinic was hard to find. They were then able to improve the sign-posting to the clinic.

For the midwifery service, there was a feeling that as a questionnaire is already given to clients at the end of their contact with a midwife that there was already an opportunity for clients to give their views. During discussion with the midwives, some commented that the results of the questionnaires went back to the hospital and were not divided up by post-code, so it was fairly difficult for them to access and learn from feedback specific to their own service.

In light of this the midwives agreed to trial an adapted version of the forms in the baby group. However, discussions with the midwives during the final observations showed that while the forms were distributed, they had not been analysed and no further forms had been used. The reason given for this by the midwives was an excessive workload which undermined their capacity to implement any new initiatives.

The final observations at the end of phase II indicated that the majority of those using these services were still unaware of this feedback option. None of those interviewed had seen any of the feedback forms in either the health visitor clinic or the midwifery baby group. The clients interviewed were quick to point out that comments forms were a good idea and that they themselves would consider using them.

> "Yeah, because if you want to complain it's difficult to do it to their face. Well I wouldn't want to anyway" (Resident Interview, Phase II).

There was also a feeling that a written comment was more likely to be acted upon.

> "If you've written it down you know its not going to them its going to their supervisors" (Resident Interview, Phase II).

Towards the end of phase II of the study, a 'family point' session was developed as part of the programme. The session aims to support parents by providing toys for 'stay and play' with younger children and access to information about other related services in the area. The programme coordinator was keen to develop the sessions so they effectively met parents needs. She wanted to try out a simpler method for getting feedback, so handed out post-it notes to the parents for them to write what they liked and what they didn't about the sessions and what information they would like in future. This very simple method was quick and easy and parents could instantly see the feedback of others in the session.

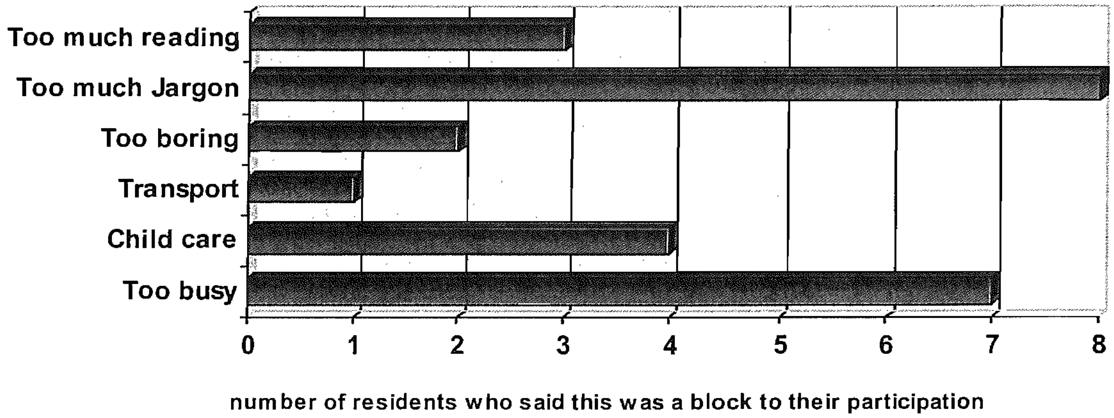
6.3.2.7 Parents' Panel

The group were very conscious that while we had tried several ways to increase the opportunities for clients to feedback ideas on the services of the family support programme, we had not as yet, encouraged any deeper levels of participation in actively shaping the design of the programme's services. The co-researchers felt that just providing feedback alone would be unlikely to stimulate some of the benefits of participation identified (see Findings I) such as building self-esteem and developing new skills.

Initially the group felt that reshaping the family support sub-group would be sufficient to improve opportunities for those who wanted to get more involved in the management of the programme. The existing structures within the wider regeneration scheme for resident participation are focused on the working groups and sub-groups described in the previous chapter (Chapter 5). However, during the study it became clear that there are several constraints to full participation of residents in the programme's sub-group, in particular the lack of decision-making role of the sub-group, its irregular meetings – only two meetings during the study period, the small number of residents – only one attending regularly and the lack of young parents represented. After much deliberation, the programme coordinator decided that due to its lack of decision-making role, the sub-group would be most useful as a networking group to improve communicate between the different family related services within regeneration area. This change in role made the co-researchers question the value of encouraging clients and community members to participate in the sub-group when they would have no real decision-making power and would not be actively redesigning and improving services.

The frustrations for residents of being involved in groups dominated by agency representatives and unable to influence the agenda and decisions taken was highlighted during the reconnaissance phase and the participation ranking exercises (see section 2.7 below). The reconnaissance phase highlighted the factors deterring new residents from attending these meetings. The graph below shows the ranking given by the 15 residents interviewed of the constraints they faced in attending such formal meetings.

Figure 17: Constraints to Involvement from Resident Questionnaire Interviews



While there are many constraints facing residents, particularly young parents – the main client base of the programme – in participating in the decision making processes of the regeneration programme as a whole, the co-researchers felt fairly powerless to change these wider structures. However, the reconnaissance study findings made us wary of establishing a group of clients and community members based on formal meetings requiring a substantial time commitment to read the relevant materials and understand the jargon and terminology. We were keen to find a way to grow parents into decision-making roles and to offer a more participatory space where clients and community members could begin to increase their self-esteem and confidence.

Due to the review of the sub-group and these concerns about formal meetings, we went through much reflection and deliberation to agree on the kind of group that might be successful. Eventually we decided on a 'Parents Panel'. The idea was to move away from formal bureaucratic-style meetings to a friendly group with a focus on planning activities to maintain interest and build the confidence of members whilst also acting as a spring-board to join the more formal decision making structures of the regeneration scheme.

> CR: "yes, but I think. ... the sub group is a format that is too formal. I mean Y {resident co-researcher} you've been to some of those sorts of meetings and you know they are not everyone's cup of tea. So I'm wondering whether that group of residents couldn't plan Family Fit that we have in May, could it plan Healthier {regeneration area} Day or our input into the festival September? So they'd have four things to do so they are all themed and then there is the review and even the summer trips. And any of the clients that use our services could be encouraged to join that group and that might help them with parenting issues as well" (Action research session 11).

Furthermore the opinions of the Parents' Panel members could be sought on specific issues and ideas being developed within the programme. The development of a new clinic in the area was seen as the ideal focus for the panel to begin to engage in and influence these issues with the community.

> "There is a possibility that in the long term that that group could have some influence over how we develop the clinic – well if we ever.. but we could have some conversations with them about what they'd like to see and they become part of that group about planning it as well" (Action Research Session 11).

As discussed in section 6.3.1.3, the issue of which residents would want to be involved in the panel caused much debate within the group. There was concern that many of the locality family worker clients were too under-confident and had such complex lives that, either in reality or in their perception, joining such a group would merely add to their stress. For some of the co-researchers there was also a concern that those with too many problems – in effect, many of the clients of the locality family workers – would be too negative to take positive actions to improve family services.

> "I think though that most who want to come are the most motivated who probably have had a bit of experience of something I would suspect. I think that is the problem, I can see you want to ask some that have had the locality family workers, but I think when you want to get something started I wouldn't have them there at the beginning it might be better to draw them in as time goes on, as I think some of them will be very negative and they will moan. And you don't want moaning people to start with" (Action Research Session 15).

As described in sections 6.3.1.2 and 6.3.1.3, information and an invitation to join the parents' panel was sent to all locality family worker clients and leaflets were displayed at relevant groups and clinics unfortunately this did not solicit any responses from any of the residents. So, the co-researchers invited parents who were already active in the various parent and toddler groups in the area, or were identified by the locality family workers as possible participants.

> "Yeah and I agree with you for the locality family workers to identify people who feel they can offer something and are in a place where they feel they can offer something. As someone might like to do it in their dreams, but just has not got the head space to do it because there are too many things going on for them." (Action Research Session 14)

The constraints of this targeting strategy are outlined above in section 6.3.1.3. The effects of the strategy were that only those already heavily involved with running parent and toddler groups in the area attended the panel. There were a total of 5 parents – all women – who attended all or most of the panel meetings. The group met three times over a period of 3 months, but decided in the third meeting that due to their existing commitments they did not want to continue with the panel. They did decide to continue to meet on a very informal basis to share experiences of running parent and toddler groups.

While the strategy of asking those already active in the community meant that the participants did actually attend the meeting, in the long term the group moved away from its original purpose precisely because of the members' level of existing activity. Hence, while the strategy of directly inviting those already active in the community did mean that five parents attended the group, ultimately it undermined the purpose and sustainability of the group.

There was some debate among the co-researchers on how to run and facilitate the sessions. All were agreed that the group should have as much autonomy as possible. The first expression of this was allowing them to change the name of the group from Parents' Panel which was chosen by the action research group, to whatever they thought most appropriate. There were also flexibility for them to decide on the location and timing of the group. The group decided not to change the name or the location of their meetings; this may be an indication of the lack of ownership they felt over the group.

The programme coordinator facilitated the first session, however the successive session were facilitated by one of the locality family workers. The co-researchers felt the group would be more likely to develop their own agenda and ways of working with minimal facilitation and very limited involvement of the programme coordinator.

> "I just think with my role then they will look to me constantly to be the chair of it and I don't want that. I want it to be driven by them. And I said to them that I can be a resource, but I don't want to be the one that directs it; otherwise I think that all the time I am there they'll look to me" (Action Research Session 16 Programme coordinator reflects on facilitating the first Parents Panel).

While the co-researchers' concern is understandable and clearly shows the desire not to dominate the panel, one of the residents interviewed as part of the final observations of Phase II expressed frustration with this approach.

> "It just didn't seem very organised and to be quite honest, it felt like they kept saying, 'we don't want to put words in your mouth or ideas into your heads, but this is what we have come up with'. If they had said, 'these are the ideas' and laid it all out on the table, 'this is the plan for this group, these are the ideas that we have these are the things we would like you to be doing'. If it was less of, 'we don't want to be putting words in your mouth' and more 'these are the ideas we have got for this group, but it is your group, so if you don't want to go with these ideas then it is fine'" (Interview with community member who joined the Parents' Panel).

The experience of setting up the parents' panel provided the programme and the co-researchers with some valuable lessons on who should be involved in such a group and how it can be run. Both these issues spring from more fundamental questions as to the nature and purpose of the group. If the group is seen as a forum for supporting those who are isolated and under-confident to become more empowered participants then clearly targeting those already active in the community is not sufficient. Clarity on the agenda of the group was also missing with members expressing a preference for more structure and transparency on the purpose of the group.

To summarise, feedback at community events proved to be an effective way of talking to parents. The concern here was to ask specific questions about the service rather than encouraging parents to come up with a ‘wish list’ of responses. While speaking to the programme coordinator directly appeared to be a straightforward way for clients to give feedback, there was concern that some clients might not feel comfortable with such a direct approach. The idea of a texting service was greeted with enthusiasm by many community members; however there was limited awareness of the existence of the service. The annual review methods of questionnaire and drop-in sessions proved an effective way for clients to give their feedback about the service and provided valuable lessons for the co-researchers in conducting similar exercises in the future. The review also provided observation data on the effectiveness of other participation strategies being used by the co-researchers. The experience of establishing a parents’ panel as a means of encouraging deeper levels of participation was particularly instructive for the co-researchers. The strategy of directly inviting those already active in the community exposed the tension between getting attendance at groups and being able to adhere to the original aim of encouraging those who would not normally get involved to become active in the design of services. With all these modes of participation there was concern among the co-researchers that only the most confident and articulate were responding. The communication strategy of using one-to-one worker support to encourage and build the confidence was felt to be the best way to engage the more isolated community members to take advantage of these various modes of participation.

6.3.3. Collation of Feedback and Views

During the year of the action-research project, much of the analysis of the client and community feedback was carried out by all the co-researchers within the action-research group. As the group included the lead health visitor and the programme coordinator who were both able to take issues from the feedback to help develop their services, this approach was pragmatic. However, the group felt that relying on the group sessions to review, reflect and decide how to act on this feedback was an unsustainable approach for analysing feedback in future. Instead we were keen that this became a routine part of the programme managers' work.

> "The locality family workers bits will come back to me and we can collate it and that will be on-going. To be honest, I think the health visitors should take responsibility for this {feedback on health visiting}, it shouldn't be me" (Action Research Session 14).

Both the lead health visitor and programme coordinator felt that analysing the feedback was not an overly time consuming task and was achievable during their existing workload. One factor that may make it difficult for the programme leads to conduct such analysis is their closeness to the services which are being commented on and criticised. Overcoming these tensions may make it difficult for the programme leads to review, analyse and respond to feedback. Sharing the feedback with others in the action-research group helped to address these issues by putting criticisms into perspective and focusing on positive solutions.

During the interview with the health visitors as part of the final observations it became clear that the lead health visitor had not shared the feedback from the feedback forms with the other health visitors. This issue was raised in the final findings feedback session with the action-research group and after reflection the health visitor agreed to discuss the feedback at team meetings.

6.3.4. Communication of Feedback and Views

The fourth component in the participation system is a mechanism for communicating the views and feedback back to the client base or wider community. The co-researchers felt that this should serve the dual purposes of increasing accountability of the programme to its constituents and also in potentially stimulating others to give their views or get involved in the programme. During the study period, the co-researchers used several community newsletters to communicate the findings of the various feedback strategies and these were linked to the proposed action, or reason for inaction.

> "If we sat down together and came up with a simple reply to take up some of these issues, and not in the jargon but in {the language the community use} and

> say this is what we've done with it and if you want more info, put a name there. There is no reason why we can't do that." (Action Research Session 6)

As described in above, we were very aware that the written word would inevitably limit the accessibility of the findings, however there were few ideas on how this could be done differently.

> "If someone could come up with another form of communication apart from the written word, I'd love it, because I don't think people read it. I send it out, but I don't think people read it. ... but I don't know how else to do it." (Action Research Session 6)

A more direct approach was taken with the findings of the annual review of the locality family worker service which were mailed out to all the past and present service users. The findings and the ways proposed for changing the service in light of the findings were summarised to two sides of A4 with some of the key graphs. During the final feedback session, the co-researchers discussed the possibilities of holding open days and displaying the results of feedback exercises within the clinics and other well-used areas. The co-researchers were quick to point out that the process of feeding back to clients and the wider community would be greatly facilitated by the building of a new clinic which will, as described in Chapter 1, bring together all the family support services of health visitors, midwives and the family workers under one roof. The constant changes in venue for various activities and services due the demolition of the old clinic, was cited by the co-researchers as a real constraint to not only encourage client and community involvement but then maintaining the contact over a period of time to be able to feedback results and update on progress in changing services.

6.3.5. Influencing Decisions

Within the participation system, the co-researchers felt that decision-makers could be influenced either by staff members representing feedback and views given by clients and the community, or community members could become directly involved in the decision-making process. The challenges in establishing the parents' panel and the constraints facing community members' involvement in the formal structures of the regeneration programme severely limited the latter option of direct participation within the decision-making process. Hence, during the study period the experience of the co-researchers focused on staff members representing and feeding community and client views to those making decisions.

As discussed in Chapter 5 the Community Health Working Group and the Board are the key decision making structures within the regeneration programme. However, for much of the day-to-day running of the family support services, the programme coordinator, lead health visitor and midwife are able to adapt and change their services. For example, in light of the feedback programme leads were able to improve the sign posting for the health visitor clinic, make adaptations to the layout of the family point sessions and reformat the locality family workers' appointment cards to provide an office number for feedback.

Chapter 5 describes how the health trusts are key partners for the programme, with all programme staff managed through the primary care or the hospital trust. Hence those able to take decisions related to the overall programme design and resources were from the health partners and the NDC regeneration scheme. This diversity of decision-makers further complicated the ability of the feedback and views of clients and the community to influence the way the service develops. These constraints are discussed in more depth in the Chapter 7.

The programme staff had several mechanisms available to influence the health and regeneration partners, including attending working group meetings, feeding findings and recommendations of the annual review to managers and feeding comments and suggestions from feedback forms, comments book and the texting service to other service leads.

There are questions about the effectiveness of all these mechanisms. For example, while the working groups appear to be ideal forums for feeding comments from clients there are still questions as to how much influence one worker can have when they go along.

> "I went to an environment working group meeting last week and they are doing their performance review. I raised things from those comments about safe play parks and provision for the children when you do live in a flat are the sort of things that people think will make it an ok place to be. We had something about play on the agenda, but they looked at me askance, they didn't get it. But in all honesty if you've got young children in a flat, how do you offer your children

> safe play, then that is an impact on what you feel about {the area} as a safe place to live" (Action Research Session 10).

During the study period there was no real evidence that programme staff had been able to influence decisions taken through the working groups. However, the recommendations from the annual review based on the feedback of the locality family worker clients did feed directly into the redesign of Phase II of the programme. Unfortunately, due to management changes and problems with the original proposal for funding, the Phase II plan has not as yet been approved by the regeneration scheme so the actual impact in terms of changes to services are yet to be seen.

6.3.6. Communicating of Impact

While the co-researchers were all in agreement of the need to let residents and clients know how their feedback had been able to change, or not change, services, as described above the time period of this study was insufficient to allow for any fundamental changes to services. The more minor changes and adaptations to the clinics and groups mentioned above were discussed with those participating in the groups on an informal basis.

6.4. 'Measuring' Participation

As described in Chapter 3 and 4, one element of the study was to explore the viability and value of measuring participation. Two methods were used to do this; firstly to collect data from local groups and services to give a one-month snap shot of attendance and secondly to conduct 'Participation Wheels' with key stakeholders - parents, the health working group, the Programme sub-group and our own action-research group. The sections below present the group attendance data collected and the results of the participation wheel exercises.

6.4.1. Group Attendance Data

Data was collected from two snap-shot months of June 2004 and January 2005 for a variety of groups a toddler play group, women's support, a youth group and the health visitors' clinic. The data collected are presented below.

Figure 18: Parents Attendance at Toddler Group

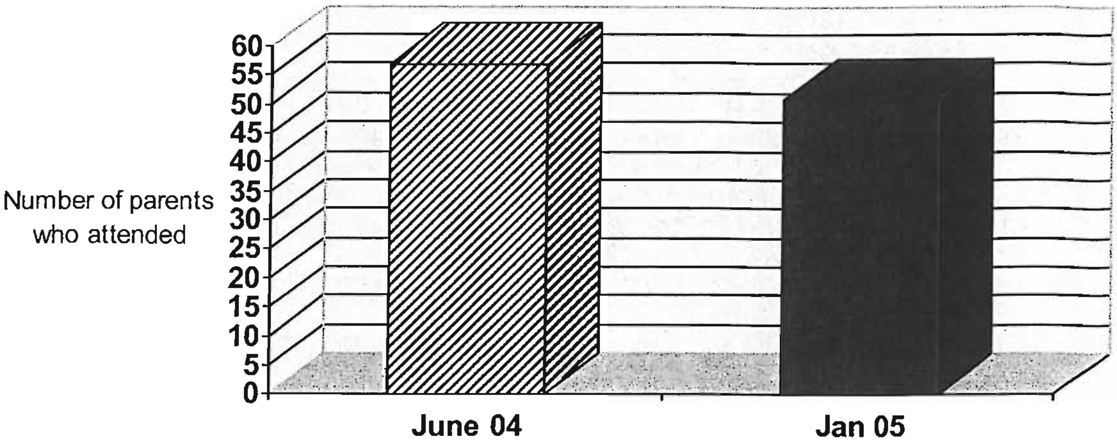


Figure 19: Attendance at Health Visitor Clinics

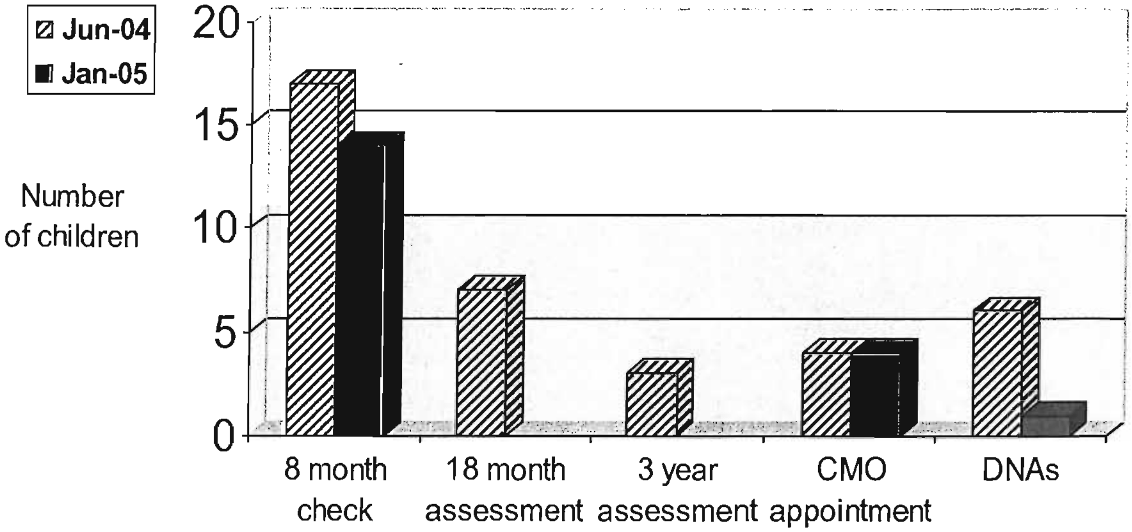


Figure 20: Youth Programme Attendance

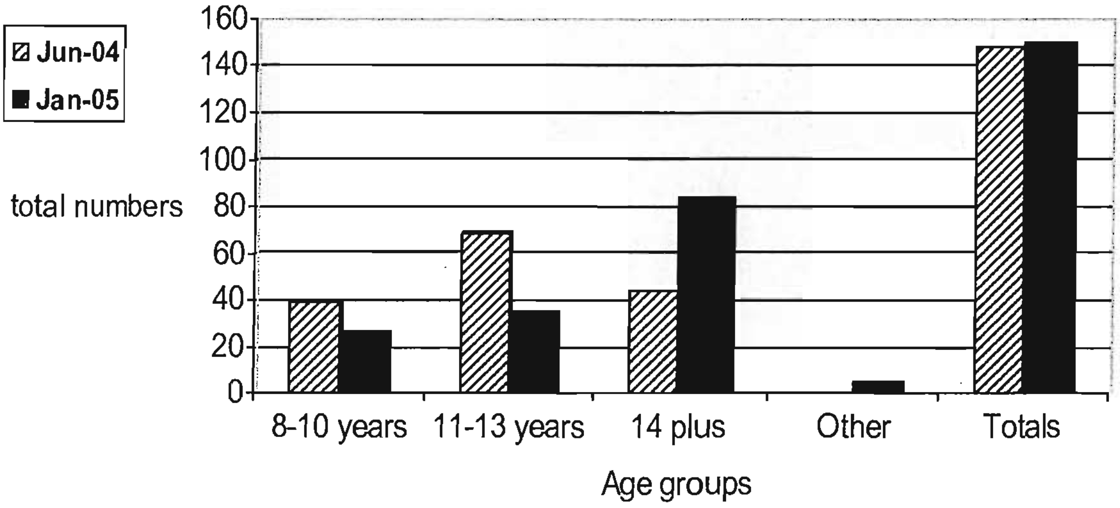
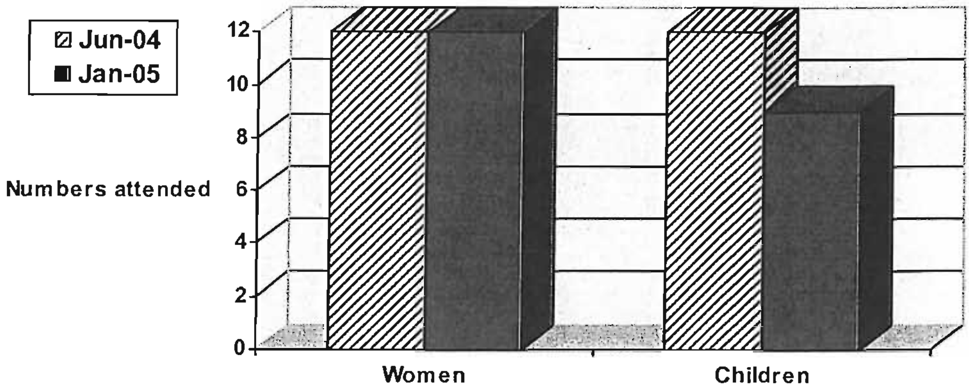


Figure 21: Women's Group Attendance



6.4.1.1. The Co-researcher's Reflection on the Value of Attendance data

Once the data had been collected, we reflected on what the data represented and how valuable it was in terms of measuring participation. The data caused much debate about the constraints of taking a one-month snapshot. For example, the low turn out in January for the parent and toddler group was felt to be due to seasonal colds and flu. Furthermore there were constraints to the quality of the data due to changes within the services over the time frame. For example the youth project changed the way they were working to increase the amount of outreach work to people's homes which may have had an impact on the numbers attending groups.

As described in Chapter 3 the programme had also been interested to see whether the data was a useful way of observing the impact of the locality family workers' role in encouraging their clients to attend clinics and sessions on an individual basis. However after some reflection we agreed that there were so many complex influences on group attendance that it was very difficult to attribute this to either the work of the locality family workers or of the strategies to encourage involvement. The overall conclusion of the group was that collecting this data was of very limited use in monitoring levels of attendance, particularly as the data had been quite time consuming to collect and collate.

6.4.2. Wheels of Participation: A Tool for Measuring, Discussion or Education?

Three of the Participation Wheels are presented below, the first from the community health working group, the second from the parents attending a parent and toddler group and the third from the action-research group. No special attempts were made to sample participants for either the working group or the parents' groups. The normal membership of the community health working group including both agency and community representatives and programme representatives were present. This meant that there were changes in the membership and those able to attend between the two measuring sessions in June and February. Similarly the participants at the parent and toddler group were merely those that would attend the group normally and again this meant that different parents participated in July and February. Due to the infrequency of the meetings of the programme's sub group and the change in its membership and focus, the second wheel was not completed by this group.

Figure 22: Community Health Working Group's Wheels of Participation

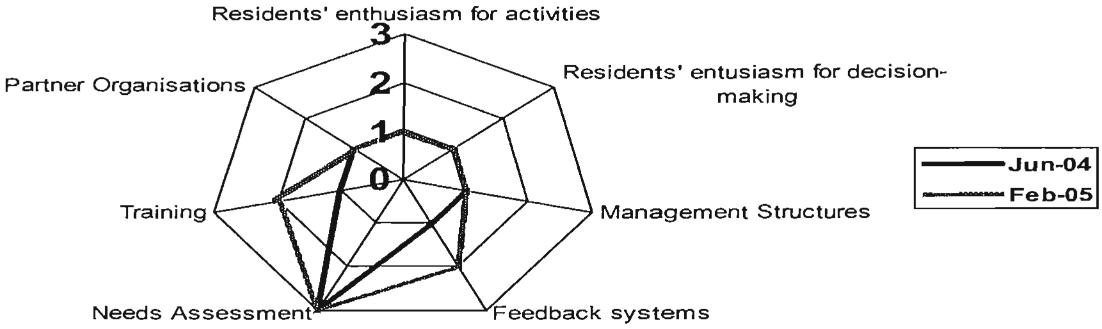


Figure 23: Parents' Wheels of Participation

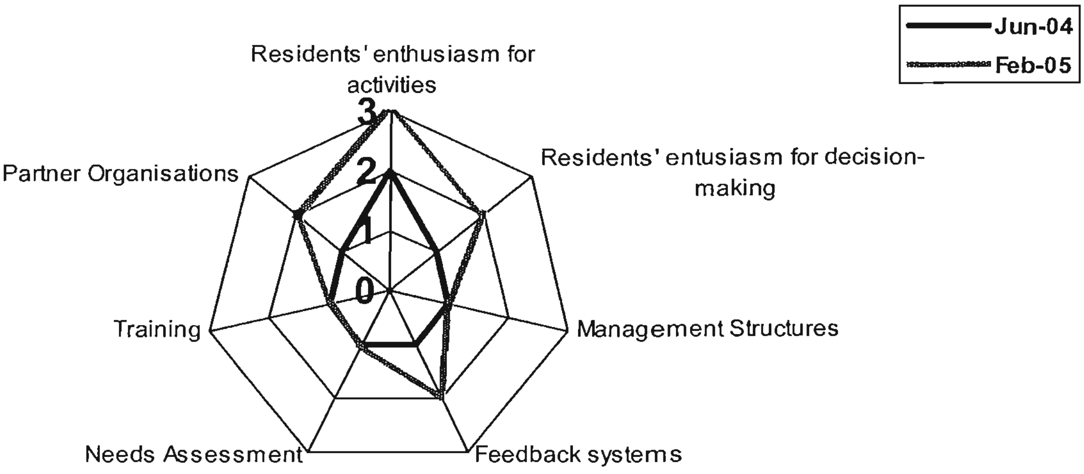
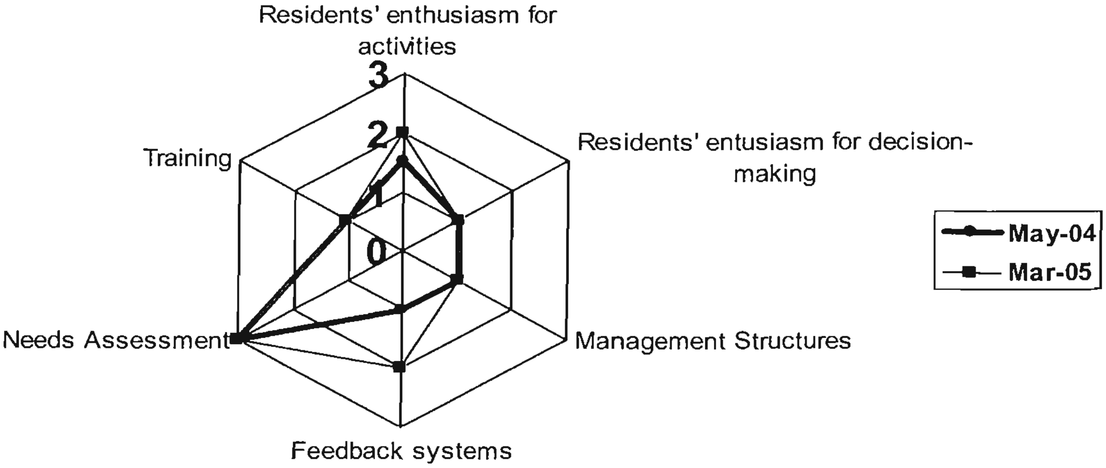


Figure 24: The Action Research Group's Wheels of Participation



6.4.2.1. Co-researchers' Reflection on the Participation Wheels: A Discussion and Educational Tool

The group were encouraged by the participation wheels as both the residents' and the community health working group's wheel show some improvements in participation levels. The community health working group felt there had been an improvement in feedback systems and in training for participation. The residents identified improvements in the feedback systems, the enthusiasm of residents to get involved in activities and decision-making and the extent to which partner organisations were attempting to encourage participation. As the action-research group, we felt that there had been improvements in the feedback systems and in resident's enthusiasm for getting involved in activities. Clearly all the wheels showed there is still much room for improvement, particularly in improving management structures to increase the extent and quality of participation in decision-making.

The fact that the wheels helped us to see that some progress was being made was a real boost to morale; however, there were some very real limitations to the participation wheels as a method for measuring participation. As mentioned above, the community health working group and the parents' group both had different participants from one session to the next, although for the community health working group some of the participants did remain the same. However, these differences make it difficult to compare the two wheels by each group.

Secondly, there was insufficient time during the meetings to achieve group consensus on what each of the points on the ranking scale represented. For example, by scoring 1 the different groups and individuals within the groups may well have had very different perceptions of what this minimal level of participation would look like and similarly when giving a ranking score of 3 there was no common definition of this higher level of participation. Even if more time had been allowed for the exercises, it is still questionable whether we would have ever reached consensus, although the discussion itself could have been very valuable.

While the wheels were not particularly useful for measuring quantifiable changes in participation within the programme, the co-researchers did feel that they were a valuable tool for triggering discussion. Through these discussions the wheels acted as a tool for educating those using them on the concept of participation, the extent to which participation was being pursued within the programme as well as hearing others' views on the possibilities for participation. For example, using the participation wheel with the parents' group helped to raise awareness of the idea of participating in a programme. The majority of parents in both the first and second groups were familiar and comfortable with the idea of getting involved in activities, but participating on a more in-depth basis in decision-making or even giving feedback on existing services was a new concept for them. This was an indication of the history of limited participation and involvement in services in the past.

For the decision-makers within the health working group, the wheel was not only a good trigger for discussion but also provided the space for the group to begin to think through why they wanted to encourage participation in the different aspects of the programme and also what the programme might be able to do in order to improve the quality of participation and move further up the spokes of the wheel in the future.

There was agreement among the co-researchers of the need to monitor changes in participation levels over time. Recording and monitoring attendance data from the key elements of the service was seen as a way of keeping a rudimentary track of levels of involvement, although recording this over a continuous period of time was felt to be more useful than collecting data over a period of a month. The participation wheels were thought to be useful if they could become an integral part of the institution's monitoring system with clear definitions for the points on the scale and used by consistent groups of both staff and residents at regular intervals. However, the co-researchers felt the wheels had greater value as an educational tool and a trigger for discussion within a workshop setting.

Conclusions

Through the action-research cycles the group were able to establish the rudimentary components of a system for facilitating both clients and the wider community to air their views about the service and for these to feed into the design and delivery of the programme. Furthermore, some steps were taken towards establishing a forum for community members and clients to influence the design and delivery of the service. The experience of the group has emphasised how important it is to see facilitating participation as a system. The group felt very strongly that merely developing one component of the system is not sufficient and can possibly undermine attempts to encourage participation. Such a system must be able to inform the community of ways to get involved, offer a range of entry points for expressing views and participation, ensure that these reach decision-makers and can influence service development and finally, that there is some means of communicating the changes that have been made or reasons changes can not be made, back to the community.

The observation stage at the end of phase II of the study showed that there is still some way to go before the participation system envisaged by the group becomes institutionalised and clients and community members are aware of and able to realise their role as active participants within all aspects of the programme. The system has been easier to develop in some aspects of the programme than others, with the locality family worker service undergoing the most changes to encourage participation. These changes have been more difficult in the midwifery service and to a lesser extent the health visiting aspects of the programme and the reasons for these difficulties will be examined in the following chapter (Chapter 7).

While some progress has clearly been made, one area that received limited attention within development of the system was *who* participates within the programme. Attempts to encourage participation were rarely targeted at those least likely to participate – often the most socially excluded. The action-research group did try to address this to a certain extent by offering a range of ways for people to get involved. However, frequently those returning feedback forms or questionnaires, or texting or attending drop-in sessions, events and parents' panel meetings were already active and involved in their community and confident to express their views.

So while the action research group are clear about the need for a system to facilitate active participation and influence programme development, in many ways they are still in the early stages of making the system a reality – particularly for the most socially excluded. The following chapter presents the thematic analysis of what helped and hindered our action-research group in thinking through and implementing this system for participation within the programme.

Chapter 7: Findings IV: What Encourages and Discourages the Development of a Participatory Programme?

The previous chapter presented the experiences of the co-researchers in trying out a number of different strategies within a broader system for encouraging clients and the wider community to participate in giving their feedback and influencing the development of services for supporting families. Action research provides an opportunity for looking beyond these contained cycles of experimentation and reflection to take a longitudinal view of the process of change over the entire duration of the study. This broader perspective is presented here and is structured according to the key themes that have emerged.

As described in Chapter 4 the key themes have emerged through the use of the framework approach to analysis. The findings in this section draw mainly on the data from the transcripts of the 16 action research sessions and individual interviews with all the co-researchers held between February 2004 and March 2005. Data from the reconnaissance phase and the observation stages throughout the study have also been drawn on. This includes transcripts from interviews of both residents and agency staff and notes from questionnaire interviews held with residents during the reconnaissance phase. Full details of the sampling procedures, interview techniques and methods of analysis are given in Chapter 4.

While the group may have been able to identify and go some way towards establishing the elements of the participation system, the final observations and the group's own reflections indicate that there is still a long way to go before this system becomes embedded in the work of the programme and begins to reap rewards in terms of an increased level and quality of participation. The factors which helped and hindered the progress of the co-researchers in establishing this system and developing their thinking on participation are presented below.

7.1. The Nature of the Area

As described in Chapter 5, the community in which the study was conducted is classified as 'deprived'. The characteristics that dominate within a deprived community were felt by many of those interviewed and by the co-researchers to undermine the possibility of increasing the quality and extent of participation. The analysis from both phases of the study identifies particular characteristics of the community that were seen by interviewees and co-researchers as challenging in encouraging participation; in particular these were the transience of the population, the real or perceived poor quality infrastructure and services, the reputation of the area, the complex lives and vulnerability of many of the residents, their lack of confidence and suspicion of those that do get involved and their negatives perceptions of statutory agencies.

7.1.1. Transient population

The community health workers felt that the transient nature of the area's population restricted the desire of residents to get involved.

> "In {the area} it's a very transient population, so a lot of people don't integrate because they think 'oh well I'll only be here a year or two and then I'll get my house...' but they never do." (Action Research Session 4)

7.1.2. Low Opinion of Local Services and Poor Reputation of the Area

Until the establishment of the regeneration scheme in 1999 the area had seen very limited investment in infrastructure and services. The co-researchers felt this had given the area's services a negative reputation and that this had encouraged those who were able to access services elsewhere to do so.

> "Like there was a lady I met... the one who was waiting for a transfer, well she does everything off the estate and I think it is a very conscious decision by some residents to chose a GP off the estate, and do everything off the estate and they will even get their kids in schools off the estate" (Action Research Session 7).

And from one of the co-researchers living in a neighbouring area:

> "They don't want to be associated with {the area}. Like I'm coming from {neighbouring area} and I know that there is that feeling. They try and get them up to the top school or they even go into the catholic system. They really do, they get them baptised so they can go to the catholic school and they are not even catholic!" (Action Research Session 7)

In the opinion of the co-researchers, this meant that those who might be more assertive and likely to get involved were unlikely to even be using the services in the area, let alone participating in their design and development.

7.1.3. Low Confidence

Those that remain to utilise services in the area were believed by the co-researchers and the majority of agency staff interviewed to be the ones with the most complex lives, those that are often most vulnerable, under-confident and therefore, least likely to get involved in community activities. This would seem to be borne out by some of the community members interviewed during the reconnaissance study. For example this resident commented that,

> "I'm one of those people who don't like crowds. I get jittery meeting new people" (Questionnaire Interview with Resident, reconnaissance phase).

Possibly related to these low levels of confidence is a sense from some in the community that those that do get involved are trying to set themselves above others. This point was raised by one of the agency staff who felt that there was a culture within the area of distrust of those that do get involved in their community and that this perception of participation as something only suitable for the 'elite' might deter others from getting involved.

> "They see them {those that get involved} as an elitist group" (Interview with agency staff, reconnaissance phase).

This point did not come out during the questionnaire interviews with community members; however this may have more to do with the difficulties of exploring issues in depth when using a fairly structured interviewing approach.

7.1.4. Previous Experience of Statutory Bodies

Interviews with agency staff during the reconnaissance phase also highlighted the view that for many residents their previous experiences of statutory bodies had been far from positive. For example, a local teacher comments on the experience many in the area have had throughout their school years.

> "They had bad experiences and they weren't taught a lot, except perhaps how to feel bad about yourself" (Interview with agency staff).

This appears to be reinforced by the health visitor's experience of trying to work with clients in the area, an experience which she has found demoralising.

> "I think that is hard for agencies as it is demoralising to work constantly with people who don't want to work with you. For me as a health visitor it is a jolly site easier working in {neighbouring middle-class area} where people are in for appointments, ring you and all that sort of thing; whereas here, you are slogging away with people who really don't want you there. It's not fair" (Action Research Session 6).

In summary, for the co-researchers there was a feeling that not only were they dealing with a community unmotivated to participate due to their belief that they would soon be moving on but also that many community members had complex needs, low confidence and self-esteem. Added to this were the previous negative experiences during interactions with statutory organisations and a negative perception of those that do get involved as an elite group.

These perceptions of the community were held with different degrees of intensity among the co-researchers. However, there were times during the action research sessions when the co-researchers, particularly the more senior professional staff, expressed their exasperation at attempting to even make an initial contact with residents let alone establish any more meaningful levels of participation.

> "I'd love to know what the community's issues are that they would come to. To be honest that's how I'm beginning to feel. So what is it that they would come to?" (Action Research Session 6)

and

> "The difficulty then is that you set it {a group} up and then no-body comes and they'll say 'well that was a waste of time'. I think that is what {one of the co-researchers} is getting at, because we know what will happen. Because we have done things before and no one has come. And everyone is tails-down again, because it's very demoralising because we try this and that and you just don't get the results" (Action Research Session 7).

7.1.5. A Sense of Realism

While all the co-researchers did show signs of being demoralised, it is interesting to note that some of the co-researchers appeared more disillusioned than others. In fact, for some, understanding the challenges facing the community helped them to be more realistic in their work with families.

> "You are working with vulnerable families but also families who know how to work the system and they know exactly what to do to get what they want, and I don't mean that disrespectfully." (Action Research Session 7)

Such awareness of the issues within the community helped some of the co-researchers to keep their expectations of the success of the participation strategies to a realistic level. It would seem that there was a balance both within the group and within the minds of the individual co-researchers with, on one hand a frustration with the many challenges to encouraging change and on the other a level of understanding and - as will be discussed later - empathy with those living their everyday lives in the midst of these challenges.

At times this realism was very valuable in helping workers to see value in taking only small steps when trying to encourage participation. For example, here the programme coordinator talks about the drop-in and comment sessions run as part of the locality family worker review. As presented in Chapter 6, only five people attended these sessions. The co-ordinator discusses a conversation she has had with another community health worker who questioned the value of running drop-in sessions for such small numbers of clients and displays how her realism and belief in taking small steps helps her to overcome the possible disillusionment of having only a minimal response to such events.

> "I pre-empted her {the more sceptical health worker} for the drop-in sessions, because she asked me and I said I know what you are going to say – 'I told you so', however, I've had two phone calls from people who apologised and said they wanted to come. It's like the more you do it....its not a reason not to do it again. I'd go back and do it again" (Co-researcher Individual Interview).

Chapter 6 highlights how some of these characteristics may potentially impact on the effectiveness of the strategies tried by the co-researchers. However working in this context has also had an impact on the community health workers themselves and in this way further influences the progress they can make in encouraging participation. At different times during the study all the co-researchers expressed some degree of frustration with the challenges of engaging with residents. For some there was however, a greater sense of disillusionment and a more negative view of the community which appeared to undermine their perseverance in trying to encourage participation. For others, while there were still elements of disillusionment, an awareness and understanding of the community had led to a sense of realism of what can be achieved. This led to a willingness to acknowledge any slight progress in developing the system and a greater determination to pursue the goal of improved participation. So while the co-researchers all felt that the characteristics of area were challenging, their different responses to these challenges shows that there are other factors at work which help or hinder the creation of a more participatory programme, these are explored in the following sections.

7.2. Lack of Power to Influence within the Organisation

7.2.1. Limited Access to Resources

While the co-researchers could influence the day-to-day running of services, as described in Chapter 6, a fairly constant sub text to the experience of co-researchers in setting up the participation system was the limited power they could exert over the more fundamental changes to the design of, or resources used by the programme. This expressed itself in a number of ways; for example the programme coordinator had no access to a budget and hence had no resources to pay for child care during community meetings or to pay expenses for community members willing to volunteer their time. This presented limitations to community members' participation on a number of levels, primarily at a fairly passive level of being able to attend groups and events.

> "Yes I'm working with one of my clients to get involved with the group that we were talking about last week. The problem at the moment is child care. She also wanted to get involved in 'Arts and Crafts' up at {a nearby venue}, but she's got no childcare so she can't do it, which is such a shame" (Co-researcher Interview).

And further, from an interview with one of the co-researchers discussing the process of setting up the Parents' Panel,

> CR1: "But even in setting up a group, you need childcare it is no good setting up a group to do anything if there is no childcare.
> F/CR: Which of course requires a budget.
> CR1: "Yes, having done sessions without childcare, as soon as the baby starts to cry the mother's off… you can't keep that train of thought and conversation going."
> (Co-researcher Interview)

The programme coordinator often displayed much ingenuity in scraping together funds or persuading other workers to help with running child care for group sessions, however as the interaction below indicates this was challenging and unsustainable.

> F/CR: "yes, we'll have to think carefully about how they {the parents' panel sessions} work.
> CR1: We should definitely provide child-care.
> CR2: But how do I pay for it?"
> F/CR: Didn't you say you could maybe get £50 or so to pay for it?
> CR2: Maybe as a one-off, but not on a regular basis"
> (Action Research Session 9).

The front-line workers, including the programme coordinator and the lead health visitor were unable to access resources for these basic expenses and were severely limited in making direct decisions about programme design. The more experienced of the co-researchers believed that there had been a shift over time removing some of the autonomy previously experienced by front line staff.

> "The trouble is I think society has become so that people who are relatively on the ground are not allowed to make decisions. Because of all the political correctness, they are not allowed to do it anymore. So the organisation is almost making decisions in a straight jacket, because the people that we need to make the decisions are running from one meeting to another and are completely inaccessible" (Action Research Session 7).

7.2.2. Working up the Hierarchy

Given the limited direct access of front line workers to resources or power to take decisions, their ability to have timely access to decision-makers further up the organisational hierarchy was of great importance. However as the quotation above indicates, getting access to senior managers was often challenging. Furthermore, structures within the health trusts and to some extent the regeneration programme were often quite convoluted, leading to delays in adapting and developing aspects of the service that could have encouraged participation.

> "'A' has looked at it as my line-manager, she said I have to show it to 'B' {next level of management}, who then passed it on to 'C' {next layer of management}! So I'm waiting for her to come round" (Action Research Session 8).

These limitations on the autonomy of front-line workers and their direct programme managers presented a real block to the development of the participation system. This was particularly apparent as the group discussed the redesign of the programme's sub group. The group were keen to encourage greater community participation in the sub group, however it became clear that senior managers with a decision-making role for the programme would be unlikely to have the time to commit to the group as the programme was only one small element of their workload. Hence within the current organisational structures and hierarchies the sub group could not have any decision making capacity.

Eventually the co-researchers agreed that its main value was as a forum for sharing ideas and approaches to family support in the area. There was concern that involving residents in a formal meeting setting was challenging enough – as described in Chapter 5 – however, encouraging community participation in these forums when ultimately they would be unable to have any control over the design or direction of the programme was felt to be of questionable benefit. Moreover that such an approach could be counterproductive as community members could well become frustrated as their views would have no impact of services.

There was some evidence that with perseverance the programme coordinator and issues raised by the co-researchers could have an impact on wider service development. For example, the development of the bid to the regeneration scheme for funding Phase II of the programme included a small budget for supporting group development which could be used to facilitate and support community meetings. The inclusion of this budget line was as a result of the programme coordinators' communication with more senior managers of the frustrating experiences of trying to establish greater involvement and support groups with no available funds. Unfortunately, the funding for Phase II of the programme had still not been agreed at the time of writing and the issue of who would be the main budget holder for these funds was still unclear.

7.2.3. Programme Coordination

As described in Chapter 5, the programme aimed to bring together the health visiting, locality family worker and midwifery services. However, while the programme coordinator was tasked to link these family support services, in practice she had no authority to manage the health visiting or midwifery components. Even the locality family workers were initially line-managed through the health visiting lead, although this responsibility did move to the programme co-ordinator towards the end of the study period. Hence her only opportunity to influence the design and delivery of these services was through either her own channels of management, or through discussion and negotiation with front line health visitors or midwives who then had to work their way through their own management structures.

> "The way the Programme was set up, it's like the jam in a sandwich, its really bizarre, as a programme leader, I'm not a midwife or a health visitor and I wouldn't want to tell them how to do it. But also I can't tell them what to do. I don't think there is a magical answer of how to do it differently" (Action Research Session 6).

As a result of this the co-researchers often expressed concern of the lack of dialogue between the three elements of the service. A new clinic is currently being built in the area and this will house the health visiting, midwifery and locality family worker services. However, during the study period these three services were scattered around different make-shift venues in the area. The co-researchers felt that the new clinic would go someway to improve levels of dialogue and communication among the family health services. However, there were concerns that a lack of dialogue and coordination between projects in the area was a feature of the NDC, not just within health but within and between the other themes.

The limitations in the influence of the programme co-ordinator and ultimately the co-researchers in developing a more participatory programme were a result of their own limited role in decision-making about their service, the inaccessibility of their own managers and added to that, the design of the programme itself with no decision making authority over the services it includes. These constraints were compounded by a lack of co-ordination between and within health and other projects in the NDC area.

7.2.4. Constant Change

Added to these constraints on the power of the co-researchers to change the way family support services functioned, was an environment of continual change and development, particularly within the health trust management. One expression of this was the ever-changing management structures for the programme. As the programme co-ordinator explains.

> "My line manager is going to change again. It will be my third line manager since I've been here. So I'm going into the health visitor management, and I'll have half a hand with A {the old line manager} as she will take responsibility for children centre development and still reporting to B {the regeneration manager} with the Health Working Group and still a handle into social services" (Action Research Session 16).

However, there were instances during the work of the action research group where the programme did appear to have greater control over their plans and activities. The experience of designing and implementing the review of the locality family worker service did show that the programme coordinator and the group had a free-reign to develop the review as they felt appropriate. The benefits of devolving authority to lower levels can be seen in this case as it allowed for the locally appropriate development of a questionnaire and drop-in sessions. Such freedom was welcomed by the co-researchers, however the group questioned whether this was a deliberate strategy by the health trust managers to allow front-line workers to have more autonomy or whether they were in fact unaware of the commitment to conduct a review, something stipulated by the regeneration programme, not by the health service:

> "I'll ask management, but I don't think they are even aware we have to do the review." (Action Research Session 9)

The complexities of working in a regeneration environment with a multiplicity of partners, all with slightly different funding, management and delivery responsibilities was continually apparent throughout the study. Hence, when the action research group were keen to make changes to try to encourage participation they were faced with not only the complexity of working within a partnership environment, but also a decision-making and budget allocation structure somewhat removed and unresponsive to their needs, these were then coupled with ever changing structures within the health services.

7.3. Lack of Organisational Commitment

The action research sessions and discussions with the co-researchers highlight a feeling in the group that while these complex, un-devolved and changing management structures do limit the power of front-line staff to take decisions and allocate resources, these were not the only reason for slow organisational movement in taking action to encourage participation. Chapter 5 describes how the regeneration scheme has community ownership as it overarching theme, the aim is that this should guide all the key theme areas of education, employment, crime, environment and health. Similarly the health service places increasing emphasis on patient and public involvement. However, there was a perception among the co-researchers that while the policy context was conducive to encouraging participation, the constraint to turning this into a reality went beyond merely managerial complexity and change and was exacerbated by the low priority given to supporting participation within both the health and regeneration programme.

7.3.1. Targets and Resources for Community Ownership

The co-researchers felt that this low commitment was particularly evident with regard to the discussion among the group on the overall outcomes of the programme and the broader health theme. The current outcomes for the health theme are closely aligned with national public health targets such as reducing teenage pregnancy and smoking cessation. The quotation below illustrates how one of the co-researchers felt that while community participation may be seen as a good way to reach these targets, without having some measure of community participation as a target in itself, the emphasis may be lost.

> "Yeah – it {community ownership} doesn't come into any of our outcomes, so maybe all they are interested in is..... whether they've given up smoking." (Action Research Session 6)

On a more practical level the group felt that this lack of commitment displayed itself in the lack of funds available to support childcare or other expenses at group sessions or any other costs that might be incurred in trying to encourage participation. Another important concern was the lack of training to build the skills and confidence of residents keen to join groups such as the parents' panel, the sub-group or community health working group. This point was particularly raised by the resident co-researcher and the locality family worker co-researchers, who felt that they had reached their current positions because of the empowering experiences of first being a member and then running parenting groups. This reflects their interpretations, presented in Chapter 6, of participation as a journey of personal development.

> "You have to be careful, don't you, of having one that overpowers the group, its group dynamics isn't it. So it might be interested to give them some training so they don't feel threatened in a group. Yeah I've been there; you are always sitting there thinking 'well should I say something?'" (Action Research Session 11).

During the study period, there was some progress in this area as the regeneration scheme began providing training for residents involved with the overall management board of the regeneration programme. However, as yet this training is not available to the wider community who may just be beginning on their own journey of participation.

The lack of progress in these areas within the regeneration programme is surprising given the emphasis on community ownership.

These concerns were reinforced by the agency interviews where several of the regeneration scheme staff felt that the structures and approaches of the scheme were not conducive to participation.

> “I think the structures don’t empower people. Too often they are geared up to the way the agencies work. Yeah and even say, sometimes we set up a project and the question they ask is how to involve the community and they pull an answer off the peg – oh we’ll set up a steering group. but people have to be more creative in terms of how they set things up instead of just looking at steering groups” (Individual Interview with agency representative, regeneration scheme, Phase I).

Too often it seems that staff within the regeneration scheme would take the most straightforward approach in order to ‘tick the participation box’ However, given the complexities of the working in the area, there were clearly some within the scheme that recognised that working in this way was not sufficient for encouraging participation.

7.3.2. Community Participation within Core Themes

A review of the documentation and discussion with staff from the regeneration scheme shows that there are some specific projects aimed at encouraging community participation. One such scheme is the ‘Neighbourhood Management’ programme which provides funds to support groups of residents to establish their own community organisations. However, support for community involvement and ownership within some of the core programmes, such as health, appears to be some way behind. For example, one of the co-researchers shares her experience of raising the issue of greater community involvement in the development of the new clinic in the area - a major project under the health theme.

> CR1: “It came up at the clinic meeting, a conversation about security, because it’s also going to have a metal shutter that will come down from the GP surgery, because people make that assumption that drugs are kept in the GP surgery. And they were talking about vandalism and I said, surely there are things that could be done with the community and they all looked at me askance. I said,

> well actually we have got some youth projects working on the estate and surely when we get to that point, the young people should be involved in the design and the planting.... All these great wonderful architect people there and the PCT planning team and they all looked at me askance. If they are involved in it they are less likely to wreck it. It's not like I was teaching them rocket-science! We have got the youth inclusion project which is working with the top 50 offenders in the community so why aren't they considering involving those people. It's ludicrous!" (Action Research Session 10)

And

> CR2: "I had the same conversation about the walk way up to the park, and I asked if they would involve the schools in it and I said you've not only got the {team who keep the area tidy} who would do some of the work, but aren't you going to involve the children in the planting to understand what is up there as then they're less likely to trash it?... but it wasn't even considered in the paper work" (Action Research Session 10).

So while, the regeneration scheme has gone some way to encouraging greater community involvement and ownership through separate projects, actually mainstreaming participation within the core themes is still limited.

7.3.3. Relations with Central Government

Issues concerning central government working were raised during the interviews with agency staff from the regeneration programme during the reconnaissance phase; there was a feeling from some of those interviewed that there was limited commitment from central government to support community involvement in practice. For example, one member of staff discussed some of the bureaucratic constraints to supporting resident participation. While the scheme are keen to pay volunteers' expenses or provide honorary payments to those who participate, many community members are concerned that if they accept these payments their benefit claims may be threaten. This has lead to a perception (as presented in Chapter 5, section 5.3.2.5.) among staff that there is a lack of commitment to participation at central government level as there has been no effort to coordinate policy at the Treasury with other departments keen to encourage community involvement

Another important issue was that of setting programme targets and outcomes. The programme conducted an extensive consultation exercise during the early stages of the regeneration scheme (Stepping Out 2000). This then generated a large number of programme outcomes and specific targets. As the programme has progressed, the Office of the Deputy Prime Minister (ODPM) recommended that each NDC scheme should reduce the number of targets to a manageable size and ensure they would help to meet nationally devised targets in each theme area. This led to a reduction from 22 health targets in the original document based on the community consultation (Stepping Out 2000) to 7 within the 2005/2006 delivery plan (Delivery Plan, 2005). While no new targets were devised, the emphasis within the reduced 7 targets is clearly aligned to national targets such as reducing teenage pregnancy and increasing fruit and vegetable intake. The resident members of the Board approved the choice of targets and they are at least in line with the original targets as agreed by the wider community. However, the influence of the central agenda over community level priorities is clear to see. For agency staff this was seen as an inevitable aspect of working within a programme funded by central govemment.

> "I think a balance has to be struck between completely ignoring national outcomes and targets and saying there is no way you can explicitly link what we are trying to do in NDC with anything that is related to national targets. To go to the extreme to say this is only about delivering local aspirations and things valued by the local community, well... but there has to be a balance between that and the people that found the money in the first place for NDC who expect to see things happen" (Interview with agency staff, Reconnaissance Phase).

There are clearly tensions between responding to issues raised locally by the community and delivering on national targets. These tensions highlight the contradictions of developing a community driven programme within an environment so influenced by central government policies and targets.

So the lack of power of frontline health workers to influence the wider issues of service delivery, coupled with the limited progress made within both the health programmes and regeneration scheme to turn the policy rhetoric into practical mechanisms to support participation was a significant obstacle to the co-researchers' attempts at establishing a working participation system.

7.3.4. A Sense of Disillusionment

This sense of powerlessness to encourage participation in the face of both immediate and more distant organisational constraints inevitable took its toll on the co-researchers' enthusiasm for trying out new approaches to encourage participation. This was particularly true of one of the more experienced workers who repeatedly expressed concerns that she would not have the power to respond to client or community views. This in turn had left her feeling demoralised and frustrated.

> "When I've done questionnaires before, and we used to have one for Parent Craft, people would always complain about the uncomfortable green chairs, over which I had no control. But if it's something that you can't change then what happens?" (Action Research Session 5).

> "I think it was when we were talking about the comments book. I mean I had no objections to asking people for what they would like, but from my experience of doing that in the past people will ask you for something that is out of your control. That then leaves you with a feeling of failure because you've asked for their opinion but you can't do anything about it. But I can understand that by asking people you are including people, but the danger is that by asking them and not providing it, they then go home and say 'well I won't bother doing that again'" (Co-Researcher Individual interview).

The findings indicate that some of the constraints to developing a participatory programme go beyond the programme staff's direct power to take decisions or find resources, beyond the commitment and support from the wider institutions of which they are part, or even beyond the challenging characteristics of a regeneration area. The findings also show a connection between the attitudes of staff towards the community, particularly their level of empathy with residents (see below section 7.4), and their desire and perseverance in developing more participatory approaches. Added to this is the further dimension of the attitudes and norms of the community health care approach and the influence this has on the way front-line workers perceive and play out their role.

Working with a disengaged, disempowered community in a deprived area through complex often disempowering organisations structures it is easy to understand why the co-researchers experienced a certain level of disillusionment with the idea of encouraging participation. However they did mange to establish some elements of a participation system and did persevere with change even in the light of considerable challenges and set backs. Different levels of enthusiasm and commitment existed among the co-researchers and it is helpful to explore what lies behind these variations in an attempt to understand further individual and organisational factors that may encourage or restrict the evolution of a participatory organisation.

7.4. Empathy with the Community

The analysis of the action research sessions highlighted different levels of empathy towards the community among the co-researchers. Furthermore, there appears to be a relationship between the level of empathy felt by the co-researchers and their ability to suggest and initiate locally appropriate methods as well as an ability to maintain individual commitment to, and enthusiasm in encouraging participation. The majority of the co-researchers either lived in, or had lived in the area, or in quite similar areas, in the past. Those that had lived in the area or similar had all brought up their children in this environment. This direct personal experience of parenting in the area appeared to increase the co-researcher's level of empathy and understanding of the community.

7.4.1. Experience of Living in the Area

Drawing on these first hand experiences benefited the group in our attempts to design appropriate participation strategies. For example the quotation below has been extracted from the discussion among the co-researchers on how best to facilitate the first session of the parents' panel. One of the co-researchers who had lived and raised her family in the area was able to draw on her experience of attempting to join parenting groups on the estate. In light of this she felt that ice-breakers and activities to welcome new participants in to the group would be needed if they were to return to future sessions.

> "Getting those {ice-breakers} in in the first week, 'cos after that's when they start disappearing and don't come back. So you need something sound at the beginning and have a good atmosphere, if they are all sat round and they don't want to talk ... its horrible, I've been there!" (Action Research Session 11)

In the following example, one of the co-researchers draws on her experience of having several small children in the area to help think through the best times to hold a drop-in session for parents to give their views and get involved in the programme.

> "With babies… attempting to be organised.. he had an early morning feed and then in the pram and then take the other two out to school and by the time you got home the baby wanted another feed. And that is how my life was at one point. And by the time you have fed baby then out to the pre-school, but if there were a few places you wanted to go to along the way, the fact that it gets to 9.30 and you've been to school, but the baby is kicking off for food, if you could go somewhere to do all that stuff and have a conversation even over a cup of coffee" (Action Research Session 12).

This level of understanding was particularly displayed by the lay member of the group. She continually acted as a 'reality-check' for the group, often pointing out how the design of services or information sheets might be inappropriate for residents, particularly for those with small children. Here she advises that the information sheet presenting findings from a feedback exercise is too wordy and inappropriate for members of the community.

> CR1: "that is too much for residents.. I'm not being rude, but if that came through my door and I wasn't involved I would bin it.
> CR2: yeah we need to get it down to one piece of paper double sided.
> CR1: I'm not being rude or anything but I know my kids, if you get something through the door, you just go flip flip flip and that's it, isn't it? Especially when you've got a kid tugging at your heels. So it's got be brief" (Action Research Session 14).

7.4.2. Professionalisation

The findings show a spectrum of attitudes among the co-researchers, at one end there is a high level of empathy and strong understanding of bringing up a family in a similar community and at the other a professional, detached approach. The transcripts of the action research sessions show how the co-researchers moved in both directions along this spectrum at different points during the study.

However, overall the different levels of professionalisation of the co-researchers did appear to influence their ability to empathise with parents in the area. For example, in the interaction presented below one of the co-researchers (CR1) – a locality family worker who has only been in post for under a year and not strongly professionalized - explains her friend's experience of feeling unable to make a complaint about her health visitor. The other co-researcher – a health professional with many years experience who has never lived in the area – responds from a professional perspective, using 'our' to demonstrate her position within the profession. She emphasises the needs of health workers within her profession on a parallel to those of the client, rather than putting the needs of the client first.

> CR1: "But it is difficult, I've got a friend who lives in {a nearby city}, a single mum who lives at the top of a walk up block and finds that she is very isolated and she had a health visitor round to try and help her with her son's sleep problems and she really did not get on with the health visitor, she had a personality clash. I said 'well phone the office, speak to the manager and ask for a different one and explain that you have a personality clash.' But it is difficult. She didn't know, she's very intelligent but she felt that she was being given a gift of a health visitor and she should just accept what she is given."
>
> CR2: "I suppose from our point of view – I guess I don't get a choice of who I should visit. I mean you say that your friend should get a choice, but then I could equally say, well I should have a choice in who I visit, I might not like her. So it works both ways, its hard to please everyone in life."
>
> CR1: "For her, she was saying that she won't see a health visitor again, and so now she is going to have this problem ad-infinitum which is no good for her." (Action Research Session 6)

The interaction below between the lay co-researcher (CR2) and health professional co-researcher (CR1) further highlights the gulf between the professional (non-resident) and non-professional (resident) approach. Here the health visitor is keen to emphasise the need for individuals to take responsibility for their own problems, to some extent this appears to be linked to her feeling of frustration of 'unrealistic expectations' placed on health visitors working to solve problems within the complexities of a deprived community. However, for the resident co-researcher this comes across as a lack of empathy with the clients.

> CR1: "Well, the number of conversations I have with people where they say I've got this problem, what are you going to do about it. And I think well hang on, you created that problem and I am very pleased to try and help you but it's your problem and not my problem! That is what it feels like as a worker on this estate sometimes – 'what are you going to do about my problem?'
>
> CR2: But good to have a bit of empathy too!
>
> CR1: Well we do, and certainly if I was speaking to you as a client I wouldn't say that to you…
>
> CR2: it's just what you'd think! {laughter}
>
> CR1: But if you come over too… if you always ask what we can do to improve, then it's always putting the onus on us to do something rather than them" (Action Research Session 9).

7.4.3. Confidence or Apathy?

Further differences of opinion emerged among the group when discussing why many residents might not take the first step to join a group or participate in any way. For the programme co-ordinator, who brought up her own children in the area, there was recognition that while many residents had the skills that would be valuable to the community, few actually get involved. This was shared by the resident co-researcher.

> CR1: "But how do we build that bridge between keeping those skills to themselves and actually sharing them with the community? How do we get to bridge that gap? We talked about apathy and time commitments, and I'm not trying to say that everyone is not bothered, because people will do anything. But how do we bridge that gap and take that step so someone can step out of those four walls? Because I know there are loads of people out there with fantastic skills, but they don't recognise them for themselves and the communities or the institutions don't recognise them.
>
> CR2: Yeah

> CR1: That's the bit that gets to me, how do you get them to take the step. I know there are loads of people out there who are hugely capable of being the boss. But they don't because they stay within their space.
>
> CR2: You need to build up support for them" (Action Research Session 3).

As described in Chapter 5, all the co-researchers agreed at some point during the action research sessions that a considerable constraint to participation was low self-esteem and a lack of confidence.

> "What about doing a little group to build up self –esteem to say this is your group, so like a foundation to build up confidence. Because I think lots of the parents just lack confidence don't they. I mean we find that all the time, that they lack self-esteem and confidence. They have got the skills, and they want to learn but they've just not had that praise, you know, 'you could do it'. I mean a small group" (Action Research Session 16).

While there did seem to be consensus among the group that many were unlikely to engage in community activities because of low confidence – and this concept was backed up by the data from the reconnaissance phase, some co-researchers seemed to give more emphasis to apathy as a major constraint. It was notable that the most experienced health professional in the group, with no personal experience of living in the area, most frequently citied apathy as key reason for a lack of engagement.

> "But there are also the people who don't do it because they've got nothing else to do, they just can't be bothered. It's fair enough if you've got something to replace it, but for lots of people round here they just can't be bothered. (Action Research Session 7)

During the analysis process the transcripts were rechecked to look for data to disconfirm or confirm the theory that it was only those who were most professionalized and living off the estate who were more likely to show limited levels of empathy with the community. For example, one of the locality family workers – who also lives and has raised her family on the estate – talks about the high levels of apathy.

> "So if you are talking about everyone working together, not just professionals but families, I don't know, because a lot of the people we are working with are

> apathetic, it'd be really hard to get them more involved. It is like prising blood out of a stone sometimes" (Action Research Session 16).

It would seem that there are complex tensions between being firmly located within the community on a personal level and working as a health professional in the community. It is worth noting that the quotation above comes from the last action research session, by this time the locality family workers had been in post for over a year and could be said to have developed stronger professional attributes.

7.5. The Health Professional Approach

Given the importance of the professional approach in influencing attitudes towards the community, it is valuable to explore whether certain characteristics of the 'professional' health worker may undermine or contradict attempts to encourage participation. The data highlights how two components of the health professional approach particularly stand out as limiting the progress to be made towards greater participation, firstly a reluctance to challenge accepted practice and secondly the direct relationship between the worker and the client.

7.5.1. The Way We Work

While unable to participate as co-researchers, the midwives were happy to discuss participation with in the midwifery programme through the Wheels of Participation exercises conducted in June 2004 and particularly in February 2005. During these discussions the midwives placed a strong emphasis on 'tried and tested' procedures. It is to be hoped that these procedures and practices emanate from the midwifery evidence base. However, there appeared to be a reluctance to look critically at these practices, particularly from the perspective of the client. As the co-researchers reflected on the wheels of participation drawn by the midwives, one co-researcher's comment helps explain this attitude.

> "It might sound awful, but they have the attitude that if you're pregnant and going to have a baby, you need the midwife and that is it. And you need our services and they are A, B and C and we don't need any feedback because that's what works and that's what you are getting" (Action Research Session 6).

While the co-researchers may have identified this attitude among the midwives, it would appear that a similar attitude prevails among health visitors. In the quotation below the health visitor expresses her difficulties in conceptualising how her service might be delivered differently. Clearly if the concept of changing the service is beyond the imagination of the health professional then it may be hard for health professionals to see the value of engaging clients or the wider community to participate in the development of the service. This difficulty in seeing beyond traditional approaches then undermines her ability to see the value of engaging with clients to hear their feedback.

> "It's a bit difficult because it's a core service, it's not like locality family workers which is a new project that you want to see is it going well. Health visiting has always been there. You could argue is it done in the best way? But I don't know, I can't get my head around it, what you could do to improve the service..." (Action Research Session 10).

7.5.2. Seeing the Bigger Picture

The data also showed a tendency for the health professionals to focus on the individual one-to-one relationship with the client at the expense of analysing and responding to wider issues about the service as a whole, or 'seeing the bigger picture'. This was particularly evident when reviewing feedback comments from clients. For example the health professional below expresses frustration at not being able to respond to individuals directly.

> "The comment about health visiting was very vague and non-specific and you can't deal with things like that. My instant thought was who said that, why did they say it, what lay behind it?" (Action Research Session 9)

This was an interesting frustration and appeared in the discussions of feedback throughout the year. The health professional was intent on improving the individual care received by the client, rather than seeing the value of feedback in changing the way a service as a whole is run to the benefit of all clients.

Similarly when planning the review of the locality family worker service, there was a strong feeling among the group that including descriptive components within the questionnaire, such as the housing type, ethnicity, age/age of children, would be unnecessary information. Some in the group felt that it would be useful to obtain the respondents' contact details so their individual concerns could be followed up. As the dialogue shows, for myself and the resident co-researcher (CR4 in this quotation), this was a missed opportunity for exploring how different aspects of the service might be improved or adapted to address the specific concerns of certain population groups.

> CR1: "I don't know that we need to know all of that stuff {descriptive information}.
> CR2: I don't think we need to know that.
> CR3: Because the service is going to be the same whether they are up the hill or in a tower block.
> F/CR: The thing is that if there are any differences in the kind of service people are getting, then…
> CR3: there shouldn't be.
> F/CR: Well, there shouldn't be, but…we need to find out if there are.
> CR1: If there are issues about the service then we'll pick that up anyway.
> CR3: You could put that as another question so, 'if there is anything you think we have missed then please feel free'…
> F/CR: I'm not saying this is an issue, but for example, you could find out that those with pre-school kids find the service great, but those with older kids have concerns about the way the service works and then you've got something for you know you have to address in the next 6 months.
> CR4: Yes I agree. It's the service that we're evaluating not the workers.
> CR2: My feeling is that if there is a problem I want to know who it is and what I can do about it, if I get something that is vague I can't deal with it.
> F/CR: Well, with a review it isn't… the point is to get people to speak openly so you can't link it to their name. It's the wrong method to find out on an individual basis what the problem is. This is a review of the service as a whole, rather than a specific person's needs" (Action Research Session 9).

For the health professionals there was a focus on improving the one-to-one work with the client. This is an indication of the way health professionals see their role; the emphasis is on the individual client, rather than the service as a whole. The findings of this study highlight how this emphasis can undermine attempts to encourage participation. As the quotations above illustrate, If the health professional does not look beyond the individual to the wider service, so the logical conclusion is to see limited value in hearing client feedback and encouraging their participation in the design of wider services. Hence a focus limited to the individual client can be seen as a constraint to encouraging participation.

7.5.3 The Role of the Professional in the Participation Journey

As described in Chapter 5, many of the co-researchers expressed a belief that participation should be seen as a journey that those who are socially excluded can make. The group also recognised that many people need the support of others to encourage them to get involved initially and then build their confidence to become more active participants.

In many ways the locality family worker service was designed to facilitate exactly this kind of one-to-one encouraging relationship. There was some discussion among the co-researchers as to whether the other components of the programme – midwifery and health visiting – would also be able to guide their clients along this journey. The conclusion reached was that while these services might be able to develop feedback systems, actively encouraging clients to participate in client or community groups developing services was beyond their perceived role.

> "So yes to the feedback, but if you are asking for a shift to get those primary care people to say, 'I'll walk the walk with you', we have got a long, long way to go. But then we are changing the role of a health visitors and midwives and where they see themselves sitting. I don't want to be defeatist because I can see were you are coming from, I mean if you do want that active participation then it is the responsibility of everyone" (Action Research Session 6).

Summary

In setting up the participation system, the action research group faced considerable challenges. The co-researchers and agency staff felt that the nature of the regeneration area presented considerable challenges for encouraging participation; many of the residents lead complex lives, have had negative experiences with statutory organisations in the past and are often uncomfortable and lack confidence to express their views or engage in group sessions or meetings.

However, these factors alone do not provide the only explanation for the difficulties in developing a participatory programme. Organisational factors such as the level of commitment and the design of the management structures of the regeneration scheme and its partner organisations were also key. These organisational factors place direct limitations on strategies for encouraging participation, by limiting resources for child-care or training for potential participants or presenting constraints to timely decision-making on programme changes. They also place indirect limitations on frontline staff by increasing a feeling of disempowerment and disillusionment which then undermines staff capacity to persevere and believe in their own agency to initiate and enact change.

Beyond these organisational factors, there are also factors of attitude and approach. The traditional approach of health professionals limited their motivation for encouraging participation. In particular a preoccupation with accepted ways of working and an emphasis on the one-to–one relationship with clients to the exclusion of seeing the service as a whole. Finally, those co-researchers with close personal links within the community - often through residency - displayed a strong sense of empathy and understanding for the situation of residents within the community. When co-researchers displayed a greater sense of empathy this helped them to preserve with participation strategies, coming up with ideas on how to engage residents and reducing the sense of disillusionment.

Conversely, a lack of empathy was associated with a view that the client and community members' lack of participation was due to apathy and that there was limited potential for creating a more participatory programme. These themes can not be taken in isolation; instead they worked in combination to undermine the attempts of the co-researchers to establish a more participatory programme. The interactions of these themes will be explored in greater depth in the following chapter.

Chapter 8: Discussion

Participation by its very nature requires an interaction between members of the community and those that constitute the institutions working within the community. This study has explored both the fields of the community and the institutions working within the community. It has particularly focused on the interaction between these two fields through a participation system and how the experience of trying to establish this system has shed light on the factors which encourage or discourage the development of a participatory programme.

The findings present the different interpretations of participation among community members and agency staff as well as their varying motivations for getting involved and encouraging greater participation respectively. The first section of this chapter explores these differences in relation to the literature. The second section focuses on the rationale for establishing a 'system' for encouraging participation and discusses the effectiveness of the strategies tried by the co-researchers. The wider organisational, attitudinal and community constraints to developing a more participatory programme are then explored. To understand these constraints better, they are grounded within the theories of new institutionalism and particularly, critical theory.

8.1. Interpretations and Motivations for Participation

The findings show significant differences between the interpretations of participation made by the agency representatives and those made by community members. For the majority of community members, participation was understood as passively attending groups or activities. Only those already active in the community understood participation to mean engaging with decisions about services within their community. This was very different from the agency representatives who, while they may have had different interpretations of the ends of the spectrum of participation, all understood participation to mean some kind of engagement with statutory organisations, rather than as a mere recipient of services through passively attending groups or activities.

This fundamental difference in interpretation of participation highlights how unfamiliar the community are with the concept of becoming actively engaged in decision making about the services in their community. Given the chequered history of statutory organisations interaction with their constituent communities (Craig and Mayo, 1995) and the limited past levels of community participation often focusing only on consultation, normally conducted via surveys (Martin and Boaz, 2000; Anastacio et al., 2000; Cornwall and Gaventa, 2001), it is hardly surprising that few residents saw participation as anything more than joining a group or attending activities. When their only engagement with statutory organisations has been passively receiving services or occasionally filling in a survey (the results of which are rarely seen), to interpret participation as active engagement in the design and development of services is something of a giant leap for many community members.

Given this gulf in the interpretation of participation, it would appear that there is much work to be done by the agencies involved in the area, particularly the regeneration scheme, in spreading the word that they are 'open for business' in terms of encouraging active participation in the design, delivery and evaluation of services. However, it must be noted that Chapter 6 highlights the co-researchers' concern that communication with the community has been a particular failing of the regeneration scheme.

In terms of motivations for participation for community members the opportunity to widen their social networks was seen as particularly important in improving their own sense of well-being and that of their children. This community perception of the benefits of social networks would seem to concur with the literature on the connection between social capital and health and well being (House, Landis & Umberson, 1988; Kasachi et al, 1997 and 1999; Baum et al. 2000). However, it must be noted that this study only explored community member's perception of benefits of participation and did not seek to identify actual improvements in health or well-being.

Another interesting finding regarding the interpretation of participation is the differences among agency staff in defining the ends of the participation spectrum. Some – particularly those within the regeneration scheme – appear to be working towards what Arnstein (1969) would call 'citizen control', however others – predominantly within the health partner organisations – were more interested in a partnership model with community members negotiating and attempting to influence existing programmes.

These differences in interpretation are further reflected in the motivations for participation identified by agency staff from both the regeneration scheme and its partners. The debate raised by Oakley (1989) as to whether participation should be seen as a means to achieving other programme objectives or whether it is a goal in itself helps in the interpretation of these findings. Oakley argues that where participation is seen as a means to achieving existing programme objectives it requires rapid community mobilisation and involvement in existing programmes, but participation is unlikely to be sustained once the programme has been completed (Oakley, 1989). The agency staff believed that participation would improve the local relevance and responsiveness of the services and programmes they were implementing and thus help them to deliver better services more able to meet their stated objectives. Here it would seem that both regeneration scheme and partner organisations are seeing participation as a means to improving programme outcomes.

However, many of the agency representatives (both from the regeneration scheme and the health partners) were also motivated by a belief that greater participation could benefit the lives of those participating, specifically by building skills and knowledge, raising self-esteem, strengthening social networks and helping individuals to take responsibility for their own health. They also felt that greater participation would lead to more sustainable programmes. Here it seems that staff are seeing participation as an end in itself which can lead to the empowerment of those participating thus enabling them to sustain programme work beyond the life of the regeneration scheme. This was certainly the predominant view among the co-researchers who saw participation as a journey where confidence can be nurtured and grown with every step along the way and that a greater degree of empowerment can be achieved through sustained and supported participation.

While much of the literature presents these approaches to participation as a means or as an end in itself as diametrically opposing perspectives, it would seem that for the agency staff and co-researchers in this study, participation can simultaneously be both a means to improved programme outcomes and an end in itself by developing more empowered citizens able to better control their own lives and the development of their communities. While there may be no immediate reason why these two perspectives might be mutually exclusive, recognition of which approach is being followed is important. To try to develop a level of participation with an end goal of greater individual empowerment and wider community control of the programme, concerted and focused actions right form the beginning of the programme is required.

While the findings did not point to any immediate problems created by the differing interpretations among agency staff, agreement between the regeneration scheme and its partners on whether participation is being sought merely to implement more effective programmes or whether the aim is to nurture empowered citizen able to control and lead development in the future is needed. For example, if citizen control really is the goal of the regeneration scheme then significant increases in investment in capacity building and support for community members to facilitate their participation are needed.

Furthermore, as several of the agency staff identified, a more participatory programme is unlikely, in the short term at least, to be more economically efficient. Acceptance by the partner organisations of these greater costs would be more likely if all partners could reach a common agreement on the justification for encouraging participation. If the regeneration scheme and its partners are seriously aiming to encourage empowered citizens with the capacity to drive forward the development of their own community then this needs to be clearly stated from the offset and built into every aspect of the work in the regeneration area.

8.2. Participation as a System

An innovation within this study has been the conceptualisation of participation as a system. However the term 'system' is used in many different contexts and it is important to clarify the nature of the participation system discussed here. The co-researchers felt strongly that addressing the components of the system in isolation of each other would not be effective and could possibly undermine the evolution of a participatory programme. Hence, the term 'system' was used by the co-researchers in accordance with its' common meaning, expressed in a standard English dictionary as:

> "Anything formed of parts placed together or adjusted into a regular and connected whole; a set of things considered as a connected whole." (Chambers Dictionary p.1679)

The participation system therefore, describes the parts that, placed together, become a connected whole which could potentially allow for the development of a participatory programme. The use of 'potentially' is important here for two reasons; firstly, the other findings from this study have shown clearly that the participation system is not enough in itself to ensure a more participatory programme. The success of the system is dependent on institutional structures, practices, cultures and the attitude and behaviour of their staff. The relationship between these factors is explored in more depth below.

The second reason why the participation system as expressed by the co-researchers is only potentially able to encourage participation is that there has not been sufficient time during this study to fully develop each component of the system and to reflect on its effectiveness as a complete process for encouraging participation. The work of the action-research group was expressed as a system to describe what we felt was needed in order to encourage participation within the programme. As the findings show we were often a considerable way from developing the various components to realise their potential in facilitating participation. The system should not and can not be seen as a blue print or prescription for participation. Not only does the system remain, in many ways aspirational for the co-researchers, but it also only tells half the story. The findings clearly show that the characteristics of the institutions in which participation is being developed, their staff and the interaction with the community are key factors in determining the success or failure of attempts to encourage participation.

While the participation system should not be taken as a blue-print, the concept of identifying the different components in the process of encouraging participation and viewing each component as contributing to the whole was important in developing our thinking as co-researchers and in guiding our actions. The literature reviewed in Chapter 2 reinforces the co-researchers' emphasis on viewing participation as a system; for example, many of the studies highlight the challenges that have faced other participation programmes in influencing decision makers (Lenaghan 1999; Fitzpatrick, Hastins and Kintrea 2000; Alborz, Wilkin and Smith, 2002; Milewa, Dowswell & Harrison 2002;). Without this clear recognition of the need to develop all aspects of the system, not only the tools and techniques of participation but also the mechanism for influencing decision-makers, the participation process is fundamentally flawed. Hence, both the modes of participation and the means of influencing decision-makers are key components within our participation system.

Others studies do conclude that there is a need to see participation tools and techniques within a broader process (Cook 2002), however none of the studies reviewed articulate the need to conceptualise participation as a system with clear definitions of each component of the system.

8.2.1. Communication with the Community

While there is much comment on the need to link consultation and other participation techniques to decision-making, there is little emphasis in the literature on the other parts of the participation system as identified by the co-researchers. In particular there is little discussion of how to effectively communicate with all groups within the community in order to stimulate and support their participation. The participation system identified by the co-researchers has three communication components: entry point communication, communication of feedback and views and communication of the impact of their participation on services. The findings show how we struggled to find ways of communicating that were accessible and appropriate for the different residents, including the most isolated within the community. The written word whether in the form of leaflets, posters or newsletter articles generated little interest among the community.

Frustration with the lack of response from these traditional approaches led the co-researchers to directly invite more active members to join groups such as the Parent's Panel. Jewkes and Murcott's (1998) study highlights how this approach is common among both the public and voluntary sectors, who instead of attempting to communicate with the broader community, hand-picked residents already active in their community to participate. The findings describe how this approach was ultimately counterproductive as community members who joined the Parent's Panel were already too overloaded as active participants to commit to yet another activity. Furthermore, it is questionable how far their views and experiences of parenting would be in line with those of the more isolated members of the community.

Through the action research cycles it became increasingly clear that the most socially isolated and least active members of the community frequently needed one-to-one support and encouragement from the programme staff in order to participate on any level. There is little discussion in the literature of the experiences of programmes that have worked with clients in this way to encourage their participation. It would be particularly interesting to explore the sustainability of such resource intensive processes. The fact that the specifics of communicating and engaging with community members in complex, socially isolated contexts has received limited attention within the participation literature is very telling. It was only by specifically identifying these communication elements as important parts of the participation system that the co-researchers were able to focus their attention on their communication approaches. The action research sessions then provided the opportunity for them to discuss the effectiveness of their approaches.

8.2.2. Modes of Participation: Tools and Techniques

The component of the participation system that does receive more coverage within the literature is the modes of participation. For example much has been written about citizen's juries, visioning workshops, comment forms and other tools and techniques. For the co-researchers, rather than developing one particularly innovative technique, we felt it would be most effective to offer a range of modes of participation to reach a greater number of community members. Thus, feedback at key events, phoning the programme co-ordinator, texting feedback, comments book, an annual review of survey and drop-in sessions, feedback forms at clinics and a parents' panel were all implemented at different times during the study.

The findings show different challenges and constraints to each technique. The techniques that relied on the written word for feedback, such as the open-ended questions within the annual review survey, the feedback forms and writing on post-its at feedback events illustrated how many were constrained in giving written feedback and in some cases concerned of comments not being anonymous. Again, close interaction with a sympathetic worker seemed to encourage more open and frank discussion of services and how they could be improved. As the action-research cycles progressed the co-researchers learnt from the implementation and reflection on these strategies and became particularly conscious of developing clear questions to generate feedback on services rather than inadvertently encouraging community members to think up a 'wish list' of general improvements to their community.

A concern raised within the literature is that surveys and other forms of feedback directed by questions identified by programme staff may merely address organisational concerns rather than issues of importance to the community (Cornwall and Gaventa, 2001). By using a variety of participation modes, particularly the open drop-in sessions during the annual review and the more detailed discussions with clients and community members during feedback events and with the parents' panel the co-researchers went some way to allowing issues to emerge from community members themselves.

With all the modes of participation tried during the study period there was a concern that only the most articulate and confident were participating. These concerns concur with the literature which clearly identifies how time and again it is the better educated and better off who participate (Schulz et al. 1995; Baum et al, 2000; Abelson, 2001). For the co-researchers this concern was continually balanced against the challenges of getting any community members to participate on any level. This was particularly apparent in the establishment of the Parents' Panel where those already active in the community were targeted to participate.

The participation techniques that allowed for one-to-one discussions between workers and community members were more successful in hearing the views and encouraging the participation of the more isolated community members. Once again this need for one-to-one worker support in both communicating with clients and community members and then listening to their views would appear to be the most effective. However, filling in surveys and forms did solicit responses and while these may have come from the more educated and articulate sections of the community, their views are still valid and of great value to the programme. The danger is that the softer, more discursive modes of participation that involved more intensive worker interaction are often not pursued and the focus is instead placed on survey and written forms of feedback (Martin and Boaz, 2000). This emphasis not only restricts the issues open for discussion by the community but also which groups within the community will be able to voice their views.

8.2.3. Influencing Decision Makers

As presented in the findings chapter, the co-researchers saw two ways for the clients and community to get involved in decision-making. Firstly, indirectly by the programme staff collating client and community feedback on services and either making changes to services themselves or if such changes were beyond their remit, to pass these up the hierarchy to other decision makers. Secondly, the more direct way was to establish a group of clients and community members who could take decisions about certain aspects of the programme.

As can be seen from the findings presented in Chapter 6, this component of the participation system and the related component of collating feedback, hardly moved beyond the early stages of development. The lack of success in establishing the Parents' Panel severely hampered the co-researchers' aspirations to encourage more active participants to directly influence decisions about the programme. Hence the main avenue for influencing decisions open to the programme was collating feedback and views and using these to directly develop services or to pass on to more senior managers.

During the study period, programme staff were able to make small changes to services in light of views expressed by clients and community members through the various modes of participation. While the changes were fairly minor, issues such as improving sign-posting and room layout are very visible to those using services. Such visible changes are a very clear way of communicating back to clients and the community that views are being heard and acted upon. The importance of explicit demonstrations of the responsiveness of staff and organisational work to participation is emphasised by Narayan (1995) who argues that this kind of responsiveness is key if the benefits of participation are to be seen in terms of more efficient, effective and sustainable programmes.

The findings describe how making wider changes to the programme, beyond the remit of the front-line workers involved in the action-research group was much more problematic. The main channels for this within the regeneration scheme was through the working groups, however representation of client and community views within these meetings did not lead to any obvious changes. From the co-researchers' perspective it would seem that these meetings are not structured in such a way to give time and weight to staff's representation of client and community views, furthermore the idea of addressing feedback within these meetings seemed a new concept to those on the working groups.

This is an interesting issue; as described in Chapter 5 the regeneration scheme has a coherent structure of working groups and a board with significant resident representation. However, as presented in section 5.2.2. and in Participation Brief II in Appendix 5, the lay members of the working groups are drawn from a small group of very active residents who may not represent the range of groups within the community. This would certainly seem to chime with other research in regeneration areas that has found similar small groups of overly-active residents (Purdue et al., 2000; Perrons & Skyers 2003). However, because the working groups have lay representation it may be that the regeneration scheme feels that this is sufficient community input into the development of services and no further mechanisms for seeking and hearing community and client views is needed. It is easy to see how this assumption may be made. However drawing on a wider body of on-going feedback can only help to increase the responsiveness and appropriateness of services. Furthermore if participation is seen as a journey towards empowerment, these feedback mechanisms can be a way to engage with community members and begin to build their interest and confidence in participating, taking the first steps on a road to greater personal and community empowerment.

One way to keep decision-makers focused on both the extent and quality of participation within their programme is by including a mechanism for 'measuring participation'. The wheels of participation conducted with various stakeholder groups during this study were valuable tools in facilitating those involved in the programme to think through different aspects of the programmes' work. By ranking each aspect of the programme there was an opportunity for representatives from different partner organisations to discuss the level of participation they envisaged and how they might be able to achieve it. By conducting these exercises regularly an organisation could really begin to work towards progress in these areas.

8.2.4. The Need for a Participation System

By clearly identifying the components of the participation system and exploring them within the action-research sessions, the co-researchers were able to experiment and reflect on different strategies for developing each of these components. While the time period of this study was insufficient to fully develop the system, its use was invaluable in guiding the activities of the group and it is hoped will continue to provide a focus for the work of the programme. The lack of attention paid to the exploration of all the components of a participation system -communication, modes of participation and mechanisms for decision-making - within both the research, policy and programme literature may offer some insights into the challenges facing so many attempts at developing participatory programmes.

The focus within the literature is predominantly on the details of these techniques. The literature on Participatory Learning and Action (PLA) techniques is a good case in point. While PLA techniques have their theoretical groundings in the work of Freire and his concepts of 'conscientisation' as a process for transforming society (Freire 1972), in practice the focus has been on the PLA techniques rather than the broader process of which they are just one part (Chambers, 1997). The same could be said for approaches such as citizen's juries. Much of the literature (Pickard, 1998; Lenaghan, 1999) has paid close attention to the details of running an effective jury through appropriate facilitation and information on the issues being debated. However, as Woodward (2000) notes there has been a more limited focus on broader issues of transforming decision-making processes so that community members can participate in a more meaningful way.

This emphasis on techniques and tools can be understood by turning to the work of critical theorists. The main proponents of critical theory have been closely associated with the Frankfurt School – or the Institute of Social Research within the University of Frankfurt. The first generation of critical theorists attached to the Frankfurt School most notably included Theodor Adorno, Max Horkheimer and Herbert Marcuse. Jurgen Habermas then critiqued the ideas of this first generation and further developed the key tenets of critical theory (Stirk, 2000). An early concern of the Frankfurt School was the dominance of positivistic science. They were concerned that science was treating the human and social world in much the same way as it treated the natural world. This had led to an overconfidence in the objective role of the observer able to identify one 'truth'. As Carr and Kemmis (1983) explain:

> "The role of science had become technical – feeding instrumental reasoning and providing the methods and principles for solving technical problems of producing given outcomes; and science itself had become doctrinaire, believing itself to have solved the essential problems of the nature of truth and diminishing the field of epistemology to the philosophy of science" (Carr and Kemmis 1983 p.130).

This 'scientistic' approach has led to a reliance on technical 'fixes'; a 'rational' approach where 'instrumental action' is seen as the solution to problems, where it is believed that it is possible to "devise, select and implement effective means to a defined end" (Sanderson, 1999 p.328). Evidence of this rational approach can be seen here with the tendency to develop tools and techniques to solve the 'problem' of participation. There is a sense that if only the right technique could be developed then the desired outcome of an active, engaged community could be achieved. However, the emphasis on designing these tools or techniques has removed attention from the broader processes of communicating with communities and then transforming organisations so that decisions are driven by community members' and clients' views and that these individuals can then play a key role in shaping the future of their communities.

Hence the desire of the co-researchers to think beyond the tools and techniques of participation – or the 'modes of participation', component 2 of the participation system, as they are described here, can be seen as an implicit recognition that technical fixes are not enough and that devising ever more sophisticated or innovative participation techniques alone can not transform the way communities interact with the institutions that work with them. Instead as co-researchers we were conscious of the need to develop effective communication both with community members and decision makers.

The participation system was our articulation of the need to focus on these broader processes, to look beyond technical fixes and develop a more coherent system for encouraging participation. Conceptualising participation as a system was helpful in that it clearly identified the different components which we needed to work on including thinking through ways to communicate with different groups in the community as well as devising a range of techniques for people to give their views and begin to participate in the programme. However, the intention here is not to present a blueprint system that can be transferred directly to other programme settings. Rather it is to recognise the importance of understanding that developing a participatory programme is more than devising ever more ingenious participation techniques; instead that attention is needed on how the programme communicates with its community and how to ensure that decisions about the programme stem directly from the views of clients and the wider community. This emphasis on the broader system of participation has been lacking in attempts to encourage participation in the past with greater attention paid to the detail of participation techniques. A good starting point for any programme trying to encourage participation is therefore to think carefully about the components of a participation system relevant to their community and organisational contexts. However, the findings from this study show that even developing a coherent system that addresses all these components is not sufficient in encouraging participation. There are significant organisational and attitudinal elements that determine the effectiveness of any attempts at encouraging participation. These will be explored in the sections below.

8.3. Interaction between Community and Institutional Fields

Action research has proved a highly appropriate approach for exploring the issue of participation. The findings regarding the participation system are of value in themselves both for the co-researchers during the study period and for others interested in developing a more participatory programme. However, analysing the overall experience of the study by drawing on the transcripts from the action research sessions and the individual interviews with the co-researchers has lead to deeper insights into what encourages and what may constrain the development of greater participation within a community health programme.

This breadth and depth of data has highlighted how while developing a coherent system for encouraging participation is vital, it is by no means the only factor influencing whether a programme will be participatory or not. The findings show how the ability of the programme to become more participatory was influenced by a series of other factors. These are the perceived nature of the area, the level of organisational commitment to participation, levels of staff empowerment, empathy with the community and aspects of the traditional health professional approach.

Pulling together ideas raised above in the section 8.1 and 8.2, these themes will be explored below through a structure which first looks at the themes related strongly to the organisations and then to the themes related more closely to the community. So, in section 8.3.1 the organisational aspects are discussed, in particular the level of organisational commitment and staff empowerment within the organisation. Section 8.3.2 then discusses the perceptions of the area, the degree of empathy felt by staff towards the community and how the traditional health professional approach colours interactions with the community. Finally the relationship between the organisational and community aspects is discussed through the lens of critical theory.

8.3.1. Organisational Dimensions: Structures and Norms

8.3.1.1. A Centrally Driven Service?

The findings indicate that there are several constraints within the programme and the regeneration scheme itself to achieving a more devolved structure. An issue raised in the findings of the study was the potential contradiction between having centralised targets and yet emphasising the community's role in determine the type and focus of projects to be implemented. While those within the scheme were quick to point out that resident members of the Board approved and agreed to any targets guiding the programme, there is still the potential that these targets may have a very different emphasis than that identified by the local community. Such centrally driven agendas can only serve to undermine attempts to act on the priorities as identified by communities themselves. Other more practical issues such as the tensions between paying participants' expenses and potentially disrupting benefits claims further undermine efforts by the scheme to encourage participation. These concerns are echoed in the mainstream NHS health services within the UK and claims that services are still centrally driven are further supported by the literature, for example, Peckham et al. (2005) argue that,

> "Whatever local views are expressed about the NHS, meeting the performance framework standards and targets remains paramount."

And conclude,

> “It is still not clear whether NHS is a central service that is locally managed, or a local service operating with central guidelines… the government still claims the latter, while actually operating the former.” (Peckham et al 2005 p. 227)

8.3.1.2. Lack of Devolution

At a more local level, the findings highlighted how the co-researchers, even those leading the health visiting, midwifery services and coordinating the programme, faced constraints in influencing anything more than the day to day running of the programme. They had very limited access to resources, with no budget to help facilitate participation by providing expenses for child care, transport or even tea and biscuits during meetings. The programme coordinator was often able to use her ingenuity to access small amounts of funds to enable some support for some of the activities of the group; however this access to resources was not structured within the programme. Furthermore, accessing those who were able to make decisions regarding resources or other programme issues was by no means straightforward with several hierarchical layers to negotiate, coupled with ever changing personnel and structures. Hence, the extent to which structures for taking decisions and allocating resources within the programme could be said to be devolved was very limited.

This lack of devolvement directly impacted on the programme’s ability to encourage participation by severely restricting the programme co-ordinators’ immediate access to resources to organise participatory events. More indirectly this lack of devolvement appeared to add to a sense of disillusionment and disempowerment among the co-researchers. With so little control over the development and resources of the programme, it is not surprising that several of the co-researchers, particularly those who had been in post for sometime, felt disinclined to encourage participation when they felt unable to respond to the views and suggestions raised by clients and the wider community. Clearly the lack of devolved structures is acting as a major constraint to establishing a more participatory programme.

The lack of devolution within primary care structures is somewhat surprising given that much of the management literature presents evidence that devolved decision-making structures provide better outcomes for patients (West et al. 2002; Borrill et al. 2000; Purcell et al. 2003). Moreover there is an emphasis on greater devolution within Department of Health policy, for example:

> "At a local level, NHS organisations will be expected to: reduce hierarchies and develop self-managed teams and build staff involvement into objectives for managers and into the performance monitoring arrangements for the NHS organisation" (DoH, 2001a p.26).

Organisational structures within both the regeneration scheme and the health services are acting on a number of levels to undermine attempts to encourage participation. On a national level, central government has some way to go before achieving a truly devolved state, and locally, complex and hierarchical management structures ensure that decision-making and access to resources is not devolved to those staff most able to facilitate participation and respond to its outcomes.

8.3.1.3. Organisational Culture: command and control?

Organisations are more than structures; the theories of New Institutionalism help us to understand that institutional frameworks have formal as well as informal elements and that,

> "Institutions are not simply administrative and political organisations; they are the sets of routines, norms and incentives that shape and constrain individuals' preferences and behaviour. Institutional rules may be consciously designed and clearly specified (as in structure plans and operating procedures) or take the form of unwritten customs and conventions." (Lowndes & Wilson, 2001 p.632)

Understanding the 'norms' of an institution is important if we are to look behind formal structures and explore why organisations run in the way they do. This is particularly helpful in understanding why front-line staff working directly with communities may not have the powers to make decisions on programme design or resourcing. Recent research on the NHS as an organisation goes some way to identifying the norms of behaviour within the health service. Farnham et al. (2003) identify a reliance on confrontation, command and control among middle managers within the NHS. They argue that if power is to be devolved then a significant cultural change must occur with middle managers developing a facilitatory role, supporting more junior staff to take on greater responsibility (Farnham et al., 2003).

8.3.1.4. Professional Culture: disempowerment

However, it is important to recognise which NHS staff were involved in this study and to consider whether they may face particular difficulties in realising greater control over the resources and decisions of their programmes. Health visitors and midwives have long been recognised as suffering a general lack of empowerment within the health profession. For example, several authors point to a disempowered nursing work force (Fulton, 1997; Bellman, 2003; McDonald, 2004), and others to the constraints facing health visitors in taking on leadership roles (Hyett, 2003). The issue is clearly articulated by Maslin-Prothero and Masterson (2002),

> "Currently in the United Kingdom, as in many parts of the world, nurses lack autonomy, accountability, and control over their working environments and the scope of their practice." (Maslin-Prothero and Masterson, 2002 p.110)

This lack of empowerment within the health profession, coupled with the command and control managerial style identified in other research may well explain the lack of devolution of decision-making and resource management within this study. The lack of devolved structures has meant that those working at the front-line are continually constrained in their attempts to open up their services to greater participation and to act on the views of clients and the wider community.

8.3.2. Community Dimensions

<u>Deprivation: a Determinant for low participation?</u>

The findings describe the perception of the community held by the co-researchers and other agency staff as well as some of the demographic statistics of the area. As described in Chapter 5, the area suffers from many of the problems found in areas of deprivation; high unemployment, a large stock of poorly maintained social housing with many high rise flats, a transient population and a greater number of single parent families that the national average. Those interviewed as part of the study discussed how these factors have resulted in a population unlikely to engage with statutory organisations.

These conditions certainly added to the challenges of encouraging participation in the area, however some of the co-researchers, particularly those that were not resident in the area, felt that these challenges would have been significantly less in more affluent areas. This point is worth exploring, if participation is extensively more difficult to achieve in deprived areas then this carries with it implications for policy and practice.

Other studies consistently point to the fact that participation is greatest among the well-educated and better off (Schulz et al. 1995; Baum et al. 2000; Abelson, J. 2001). These studies also recognise that even in more affluent communities there are those that don't participate and these are often the socially excluded. So while there will inevitably be a greater number of better educated and better off people in more affluent areas willing to give their views and to participate in a more meaningful way, if the aim is to achieve participation opportunities for *all* then this is still challenging in more affluent areas. Again this point brings us to the motivations for participation; if programme staff are only encouraging some level of participation in order to meet policy requirements then merely achieving a greater quantity of participants will be easier in better educated, more affluent areas. However, if the motivation is to encourage participation as a way of empowering individuals and strengthening community ownership of the programme then a concerted effort to encourage those whose voice is rarely heard is also needed and the quality of participation is of vital importance. It can be argued that this is as challenging in more affluent areas as it is in deprived areas.

Whether the area is deprived or more affluent it appears that there will always be challenges to encouraging participation. The important issue is to develop a detailed understanding of the community and the particular constraints facing various groups within the community. Jewkes and Murcott (1996) emphasise the importance of not seeing 'community' as one homogenous body. There is another concern raised in the literature that may help to explain the perception held by some of the co-researchers that encouraging participation in a deprived area is more difficult than in an affluent area. Several studies highlight how the images of certain groups in the community, such as the elderly or mentally ill, as 'helpless' colours the perceptions of health workers and leads them to assume that they don't have the capacity to give an opinion (Lindow & Morris 1995; Onyx & Benton in Craig & Mayo,1995; Jewkes & Murcott, 1998). In a deprived area such as this one, levels of mental illness are higher than in more affluent areas and this could potentially influence the perception by some health workers of community members' capacity to voice their opinion.

It could also be argued that because of the specific target group of the programme – families with children to 17 years – encouraging participation could actually be less challenging than for some other groups in the community. It is interesting to refer back to the motivations given by community members for getting involved, with many expressing a desire to get out of the house, meet new people and get involved in activities that could benefit themselves and their children. Clearly, many were eager to get involved and it could be argued that it is just a matter of tapping into this enthusiasm and developing a participation system that is appropriate for channelling their involvement into meaningful participation.

Hence, the perception among some of the co-researchers that encouraging participation is particularly difficult in a deprived area can be challenged on a number of levels, primarily that participation for all is likely to be problematic in any environment, but also that the perceptions health workers have of their community may actually cloud their motivation in trying to encourage participation. This is particularly true when the target population of the programme are by the very nature of being a parent, enthusiastic for some level of involvement.

8.3.3. Merging of Institution and Community

8.3.3.1. Differences in Empathy

The findings show some interesting differences in levels of empathy between health workers living outside the community and those that have lived and brought up their own children in the area. The differences were particularly striking between the non-staff co-researcher who was resident in the area and the non-resident health worker. An illustration of these less empathetic attitudes is displayed through the belief that the reason for limited participation was a sense of apathy within the community. By contrast those with more empathetic attitudes were more likely to emphasise that a lack of confidence and low self esteem, rather than apathy, were holding clients and community members back.

Resident staff with more empathetic attitudes were more likely to acknowledge that organisational policies and practices were often responsible for restricting participation, a point they found frustrating as they believed strongly that participation was of benefit to both the individual and the development of the community. For professionals with lower levels of empathy there was a tendency to see limited value in participation, often fuelled by a sense of disillusionment with the possibility for change within their organisations. Furthermore, there was a tendency among the least empathetic to put the needs of staff on an equal level with, or even above the needs of the community.

Figure 25: Empathy of Co-Researchers to the Community

Less Empathetic, more likely to believe:
- Residents are apathetic
- Limited value of participation, change is rarely possible
- Staff needs equal to/over clients'

More Empathetic, more likely to believe:
- Residents have skills, but they need nurturing
- Institutions restrict participation
- Participation vital for community development
- Community needs over staff

Figure 25 above illustrates this spectrum of empathy and the impact levels of empathy had on the beliefs of the co-researchers. It should be noted that the positioning of the co-researchers along this spectrum was by no means static and, as mentioned in the findings, it was noticeable that as the resident locality family workers spent more time in their new staff role they moved closer towards the less-empathetic end of the spectrum.

It is worth exploring the reasons behind these differing levels of empathy and asking whether it is inevitable that those from outside an area should be less empathetic and hence less motivated to preserve in encouraging participation. Certainly the personal experience of many of the resident staff and also the resident non-staff co-researcher of joining a parent support group in a fairly passive role and then developing the confidence to take a more active role had clearly helped in developing an empathetic attitude towards community members and clients who might still find active participation daunting.

Such empathy helped them to better design and develop the participation techniques and gave them an appreciation of the importance of one-to-one worker support in encouraging the less confident to become more active participants. Moreover, this personal experience of the journey of participation gave these co-researchers a unique insight into the rationale for the value of participation as a something beyond merely a means for meeting policy targets or achieving more effective programmes (Oakley, 1989). They were able to see the potential for participation to lead to empowerment, on an individual level at least. So, we can see that once again, the motivations for encouraging participation are of great importance. Recognising the potential for participation to lead to individual, and possibly community, empowerment encourages programme staff to persevere with attempts at encouraging participation, rather than assuming that community members are apathetic and little value can come of their participation.

8.3.3.2. Attitude of Health Professionals

Linked to their personal appreciation of the possibility that participation can lead to a greater sense of empowerment, was the resident and resident staff members' understanding of the day-to-day lives and challenges facing those living in the area. This level of empathy was hard for the non-resident co-researchers to achieve. However it is also interesting to see how this lack of empathy may be connected with the health professional attitude. For example Jewkes and Murcott's (1996) study exploring health worker attitudes highlights how many do not see themselves as part of the community they serve. Such attitudes can only help to undermine levels of empathy further by developing a 'them and us' mentality. Kennedy's (2001) study explores these attitudes further and finds that health workers recruited from the local community were unlikely to display such 'them and us' attitudes and furthermore, that their involvement in the programme played a significant role in shifting the thinking and approach of more traditional health professionals to develop a greater understanding of the value of local knowledge and skills.

The work of critical theorists helps in understanding the perceived differences between health workers and the communities in which they work. The recognition given by critical theorists of the dominance of a 'scientism' emphasising objective knowledge, sheds some light on the reasons why health professionals may set themselves apart from their communities. Hence the objective scientific knowledge of health professional is seen as more valid than the practical and tacit knowledge of the community. Studies by Lindow and Morris (1995), and by Onyx and Benton (in Craig & Mayo, 1995) illustrate how the weight given to the professional perspective outweighs client perspectives and as Sanderson argues,

> "consequently the attitudes and perceptions of health and welfare professionals play a predominant role in assessment and decision-making." (Sanderson, 1999 p.332).

These differences placed on the value of health professional knowledge and that of community members goes some way to explain the 'them and us' attitudes displayed by the health workers. Drawing on the findings of this study it would appear however that where this professional, objective knowledge is combined with personal experience of living within the community, greater value and understanding may be given to the experiences of community members.

The traditional health worker approach would seem to undermine attempts to encourage participation not only because of attitudes towards the community, but also in terms of understanding of the role of health workers. The findings illustrate how health workers emphasised the importance of their one-to-one relationship with clients to the exclusion of seeing the 'bigger picture' where feedback and client views would be seen as invaluable in developing the whole service. This health worker approach is identified by Hyett (2003) who notes, "the traditional role of the health visitor has been to work independently in the community, meeting their clients' needs." (Hyett 2003, p.229). This independent approach means that health workers are often disengaged from the wider development of their service and thus can see little value in hearing client views above merely improving the one-to-one work they are doing with the client. This disengagement may in part be explained by the disempowerment of nurses and health visitors discussed above.

There is an increasing recognition in the literature of the need to address the attitudes of programme staff and organisational cultures (Narayan, 1995; Chambers, 2002). For example Kelly and Van Vlaenderen's (1996) study of a South African community development organisation concludes that it is not only community members who need support and encouragement to participate, but that programme staff need training and support to re-orientate the way they work in order to enable participation, "educational preparation is needed to facilitate the transition from provider to partner." (Kelly & Van Vlaenderen, 1996 p.1242). From this study it would seem that more than educational preparation is needed, rather an attitudinal shift to develop a great sense of empathy with the community and through this empathy to increase the value given to the knowledge and experiences of community members.

8.4. Through the Lens of Critical Theory

By looking at both the community and the organisational spheres a deeper understanding of the constraints to establishing a system for encouraging participation can be gained. Drawing further on critical theory, Habermas' (1987) concepts of 'lifeworld' and 'systems' and analysis of how these two fields interacts, helps further deepen this understanding. In the 'Theory of Communicative Action' (1987) Habermas explores the domination of scientism identified by earlier critical theorists such as Theodor Adorno, Max Horkheimer and Herbert Marcuse in their critique of the Enlightenment. These earlier critical theorists emphasised how the pursuit of reason dominated by scientism had only led to irrationality and repression within society. They argued that while society had been constructed by human agency, through the positivist reason of the enlightenment it had escaped human control. Society can then be seen as a natural process beyond the control of human agency (Stirk, 2000).

While this led the early critical theorists to take a pessimistic view, believing that the only way out of this dilemma was through revolution, Habermas instead worked to disentangle, "'reason' in its communicative form, as a positive force, from rational domination, as a negative social condition" (Roberts and Crossley, 2004 p.7). For Habermas the Enlightenment and its process of rationalisation could be positive and did not only have to lead only to a 'totally administered society', but could also potentially foster a more democratic and enlightened way of living (Stirk, 2000).

Habermas (1987) does argue that currently it is the totally administered society that has won through. He contends that this has happened because economic and political systems have become decoupled from the communicatively rational sphere of everyday life. Habermas names this sphere of everyday life the 'lifeworld' (Habermas 1987). In theory of Communicative Action (1987) Habermas talks about the colonisation of the lifeworld.

> "The thesis of the colonisation of the lifeworld posits that the economic and political systems, having been decoupled from the lifeworld are now expanding back into it in a manner which is corrosive of it. Ever more areas of social life are either bureaucratised or commodified, such that the potential for communicative engagement and reasoning within them is undermined and open dialogue is replaced by bureaucratic procedures and economic transactions" (Roberts and Crossley, 2004 p.9).

Habermas' theories of the colonisation of the lifeworld helps in understanding the constraints facing the co-researchers in establishing the participation system. On the side of the organisations, the hierarchical structures and lack of responsiveness in terms of decisions and resources to the views of the community can all be seen as the decoupling of the regeneration and partnership organisations from the lifeworld. The history of statutory organisations engagement with their communities has been characterised by the decoupling to a point where , "rational dialogue between citizens, and between citizens and the state, is replaced by systemic and strategic exchanges of power" (Roberts and Crossley, 2004 p.8). While on paper both the regeneration and partner organisations appear keen to 'recouple' with the lifeworld opening up their systems to be influenced through dialogue with their citizens, in practice the organisations are still characterised by bureaucratisation. Habermas argues that this process of colonisation dramatically reduces the opportunity for citizens to engage with the state. Habermas' latter work then explores how this lack of opportunity for engagement has then resulted in the development of interest groups whose relationship with the state then becomes confrontational.

> "Colonisation, qua both bureaucratisation and comodification, contributes to the shrinking of the public sphere. Having stirred up a hornets' nest it reduces the formal opportunity for issues to be discussed, thereby prompting interested parties to set up their own discussion forums (and protests) outside of the formal political channels." (Roberts and Crossley, 2004 p.9)

So while, those within the regeneration and partner organisations may be keen to encourage participation and their policies even state that this is the direction they should be taking, the organisations themselves show characteristics that suggest they are already decoupled from the lifeworld and have been so dominated by the instrumental rationality of positivism that they could be said to have become akin to natural processes beyond human control.

From the community perspective, or lifeworld, Habermas argues that this process of colonisation has undermined the experiences of those external to state organisations. As Stirk (2000) explains,

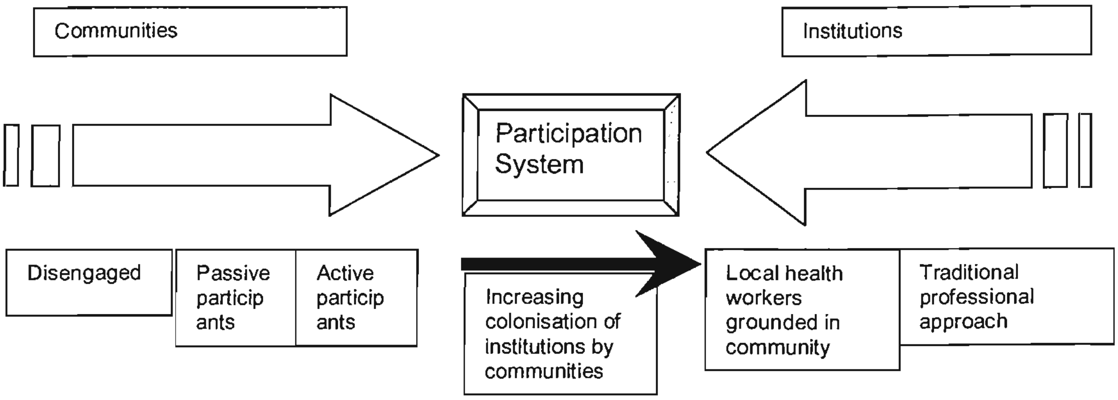
> "The colonisation of the lifeworld also has, Habermas argues, a debilitating effect upon the 'experiential context of lifeworld practices'. In part this colonisation merely refers to the subordination of men to the dictates of market processes. Here it is the restriction of self-determination by heteronymously defined occupation roles and the reduction of the citizen to the role of a consumer that is the focus. In part it refers to the effects of increasing intervention by agencies of the state in areas of life previously considered to constitute part of the private sphere. Although intended to protect individuals

> against the vagaries of market processes, these interventionalists tend to restrict individual self-determination by defining the individual as a ‘client’ of the state agencies” (Stirk, 2000 p.38).

This provides an interesting lens through which to explore the relationship of the health workers to their ‘clients’ and the wider community. While the health workers are clearly trying to protect individuals and their families from threats to their health and well-being, whose roots causes can be traced to the structural ‘vagaries of market processes’, are they in fact restricting their ‘individual self-determination’? The findings from this study would suggest there is a certain degree of tension in the approach of health workers in the community. The more traditional approach may well place emphasis on the passive client role, and certainly the more longstanding health workers involved in this study did display such tendencies with a focus on providing the services as they have always been provided and seeing limited value in hearing client views on how they can be changed. However, the findings also highlighted the more empathetic approaches of the health workers who had personal experience of living in the area. Here the client was not seen as distant from the health workers and the ‘them and us’ attitude was less prevalent. Their motivation for encouraging participation leading to eventual self-determination was built on personal experience thus strengthening their motivation for preserving with participatory approaches within their work.

It would seem that the relationship between state agencies and the ‘lifeworld’ is shifting. The policy environment is opening up spaces for communities to engage with both health and regeneration organisations. Furthermore, by recruiting staff from the communities where these organisations work, communities are further able to ‘colonise’ the statutory organisations. The diagram below illustrates this interaction between the communities and their institutions, showing how the participation system is the point at which they meet, but also showing how the engagement of active participants within the structures of institutions and the recruitment of local health workers are beginning a process of ‘recolonisation’ of the institutions by the community.

Figure 26: The Meeting of the Community and Institutional Worlds



However, the constraints to encouraging participation identified in the findings of this study illustrate how entrenched the bureaucratised, 'decoupled' approach of the regeneration and partner organisations still is. While there are clearly positive signs in terms of the growing number of local health workers and community members engaging with the organisations and the challenge they pose to traditional approaches, these challenges are met with entrenched bureaucratic approaches that do not support the flexibility and openness needed to encourage participation. Habermas (1979) identifies 'communicative rationality' as the way to move beyond these entrenched relationships.

As discussed in Chapter 2, Habermas (1979) sees the 'ideal speech act' as a prerequisite for addressing these contradictions between the lifeworld and the systems and structures of institution. The emphasis here is on developing settings where "all assertions are equally open to critical scrutiny, without fear or favour" (Reason and Bradbury, 2000). The ideal speech act has four validity claims which can be asked of any communication, they are; "is the utterance comprehensible? Is it true (in the sense of accuracy)? Is it right and morally appropriate? And is it sincerely or truthfully stated?" (Reason and Bradbury, 2000 p.93).

Determining whether communication fits within this ideal speech act starts a process of critical engagement. By asking these questions a great emphasis is placed on reflection by both the speaker and the receiver. This reflection and critical engagement has influenced the development of action research as an approach. By using this approach to bring together community members and different levels and types of staff, this study has gone some way to trigger the co-researchers to begin to look at these questions in terms of their work in developing the participation system. The aim now is for the participation system to become further embedded within the institutions and the community so that it can offer the space for others to engage in this process of reflection and critical engagement. Sanderson (1999) emphasises how developing some form of communicative participative space, such as that encapsulated within the participation system offers a way of transforming organisations,

> "The discursive model of practical discourse provides the best hope of moving forward towards an enhanced rationality of policy making – towards more responsible and effective government – not through the application by experts of objective knowledge achieved through scientific enquiry to identify 'correct action', but rather institutionalised discourse – the open debate of alternative interpretations and perspective which recognises their moral basis and seeks a consensus on what would constitute 'appropriate action' supported by 'good reasons'" (Sanderson, 1999 p. 331).

However, the degree of decoupling that has occurred between the organisations involved in this study and their communities and the hierarchical bureaucracies that have developed require that these spaces for reflection and critical engagement need to be opened up throughout the organisation, beyond a participation system that draws the organisation closer to the community. Habermas' ideal speech validity claims need to form the basis of a transformation of the organisational structures and norms, challenging traditional approaches to become open to the views and active participation of the communities with which they work. To build such communicative rationality the boundaries between institutions and communities need to continue to blur, professionals coming closer to ground level, institutions devolving and opening up to participation on communities' terms.

However, the lack of clarity between and with the regeneration scheme and its partners on their motivation for encouraging participation makes the move towards greater communicative rationality through strong participatory systems unlikely. For participative communicative spaces to develop throughout the regeneration and partner organisations clarity is needed that this is the true goal of the organisation and the value of participation is understood by all, from programme staff to decision makers. Only then can the organisation begin to develop communicative rationality with their communities.

Chapter 9: Conclusions

While the study has shown some successes in encouraging participation it has also demonstrated many challenges. This is somewhat surprising given that it was conducted in a regeneration area with a specific mandate for community engagement. The action research approach used in the study helped focus the co-researchers in initiating the development of a coherent system for encouraging participation. The more in-depth analysis of the co-researchers' experiences offered further insights into the constraints to encouraging participation within a programme of this nature. From this analysis it is clear that while developing a participation system is important, alone it is not enough. Considerable challenges remain within the structures, culture and attitudes of the health and regeneration organisations involved in the area.

This chapter begins with some reflections on the experience and value of the action research approach used in this study and then discusses some of the study's limitations. Further conclusions are then drawn from the findings and discussion presented earlier in the thesis. Recommendations are given throughout the text as they relate to the conclusions presented and then summarised at the end of the chapter.

9.1. The Value of Action Research

The action research approach used in the study proved effective at not only allowing the co-researchers to try out different approaches, but also in providing insights into the constraints facing workers in encouraging participation. The action research group benefited greatly from the diversity of its members, including health workers of various levels of seniority and a resident. The resident member was able to play a vital role in challenging the views and preconceptions of health professionals and others in the group.

Given the importance of staff attitudes in encouraging participation, action research offers the ideal forum for staff to talk through their own understandings of and motivations for participation. Ensuring a diverse membership that includes community members within the group, attitudes can be challenged in a constructive way. This study with its rigorous observation and analysis over a considerable period of time, has illustrated how action research can be used to understand the functioning of organisations. Within the participation literature this approach is unusual; there is instead an emphasis on short-term pieces of research. While these provide important insights into some of the constraints to participation, they offer only a snapshot of organisational and community experiences. The approach of this study has allowed a longitudinal exploration of the complex factors at play in a community health programme attempting to encourage participation.

Recommendation 1

Health and regeneration organisations could utilise action research approaches more extensively in order to improve practice, offer a 'safe' space to encourage attitudinal change among staff and to develop greater understanding of the complexities within organisations.

9.2. Reflections on Experiences and Limitations of the Study

When considering the limitations of the study it is helpful to think through how success of this kind of action research approach might be assessed. As the facilitator/researcher of the study this question was the subject of much of my own reflections. Throughout the study I considered whether success should be measured by the study's ability to encourage participation within the programme or instead on its ability to offer insights into the factors which constrain and enable those within the community health programme to improve the quantity and quality of participation in their work. To a certain extent this study has tried to fulfil both of these roles and this has caused tensions between the action and the research elements.

To some extent, these tensions have been exacerbated by my own background in community development; on many occasions throughout the study my desire to see improvements to the programme had to be balanced against my actual role as a research student. I was not a member of the programme staff able to make direct changes myself, but instead played the role of an external researcher facilitating others to make these changes. In this way, the research element of the study can be said to have been more dominant. Whether this is seen as a limitation depends on who is being asked. For the programme staff and the community in the regeneration area this may well be seen as a limitation, as it could be argued that with a greater emphasis on *action* perhaps more could have been achieved in terms of increased participation. However, for those external to the study area involved in policy development, the insights into the organisational constraints to encouraging participation offered by this study are particularly valuable.

When considering the value of the study for wider health and regeneration policy and practice it is important to consider the transferability of the findings. It must be noted that the action research study centred on a small group of co-researchers in only one community health programme in one regeneration area. Details of the context of the study have been presented in Chapter 5; this should enable readers to assess for themselves the relevance of the findings to their own work and decide whether the findings may be transferable to their own work or community. Furthermore, the steps taken to ensure validity and rigour within the study have been made explicit and the depth of understanding acquired through the detailed involvement with the programme and the longitudinal nature of the study should increase the readers' confidence in the findings and their suitability for transfer. During feedback sessions with local health and regeneration bodies, the findings have certainly appeared to chime with others working on similar programmes indicating that, within the region at least, there is some degree of transferability of findings.

9.3. The Contribution of the Study

Whilst needing to be taken within the context of the programme and community where the study was conducted, the findings do offer valuable insights in several areas, specifically the meanings and motivations for participation among agency staff and residents, approaches for encouraging participation and organisational constraints to developing a more participatory programme.

9.3.1. Participation as a Journey

There was a clear disjunction between the meanings ascribed to participation by residents and by agency staff. While agency staff were able to articulate a spectrum of participation levels, many of the residents were unaware of the potential to participate in any way beyond merely attending family support groups and activities. Exploring these different perspectives on the meaning of participation helped the co-researchers to develop their own ideas of participation as a journey in which the participant moves from a state of low confidence and self-esteem towards a greater sense of agency both as an individual and within their community. By seeing participation as a journey, the co-researchers inherently recognised the value of community members' more passive involvement in groups and activities. This presented a practical way to engage with community members and begin to build their confidence to participate on a deeper level. In the same way, limited participation in the form of providing feedback was also seen by the co-researchers as one of the first steps to potentially developing greater participation and a sense of agency.

While many of the definitions found in the literature are valuable in developing an understanding of the spectrum of interpretations and motivations for participation, this study has shown how a more dynamic definition of participation as a journey has practical utilisation. Hence, the definition that has emerged from this study urges that participation is seen as a process of development through which the participant is supported, facilitated and encouraged to move from being a passive to an active participant. This more dynamic definition of participation as a journey is a valuable addition to the participation debate and to those attempting to encouraging participation in practice.

Understanding the meanings different groups ascribed to participation and their motivations for either participating or encouraging participation helped the co-researchers be more aware of their own attitudes towards participation. It was here that the first differences between residents and outside professionals started to emerge. Those from the locality who had themselves experienced a process of personal development through their own journey of participation were keen to emphasise the process of confidence-building needed to help others along that journey. From the more professional stand point, to a certain extent, participation was seen as a way to achieve better outcomes and at worst, a programme obligation to be fulfilled.

9.3.2. Participation as a System

An innovation within this study was the conceptualisation of participation as a system. By developing all components of the participation system, emphasis is placed on much more than the mere development of innovative participation techniques. Attention is also paid to how and when the programme communicates with the community – and not just those that are easier for the programme to reach – and who ensures that community views influence decisions and how this is done.

The experience of this study shows that the programme was still some way from fully developing all these components. However, the co-researchers' recognition of the need to address all these areas may help in developing a coherent participation system in the future. There are no blue-prints on how to set up a participatory programme, however identifying these components was helpful to the co-researchers. Given the evidence presented in the literature review it would seem that many programmes trying to encourage participation ignore one or more of these components, and as a result either have very limited participation or the participation has very limited influence on programme development.

Recommendation 2:
For those within policy and practice development to recognise the importance of all components of the participation system including communication, participation techniques and mechanisms for ensuring those participating or results of their participation influence decisions taken.

9.3.3. Lessons Learnt on Encouraging Participation

While the progress made in setting up the system within the programme was fairly limited - generating some degree of feedback, but no greater participation and only some limited attempts to reach the socially excluded – many lessons were learned by the co-researchers and the wider programme. For example, the one to one interaction offered by the family workers was found to be particularly valuable in communicating information about events and structures for participation and also in supporting the less-confident to take the first steps on their participation journey. The use of a range of different methods for encouraging feedback and participation was vital in reaching a wider group of community members. Furthermore, the use of the participation wheels as a way for different stakeholder groups to rank participation levels, was a good way of keeping participation on the agenda of the wider organisation, whilst also acting as a educational tool on the value and levels of participation. If used regularly this could be a way for organisations to concentrate on improving specific areas where participation may be problematic.

Recommendation 3:
To reduce the reliance on the written word as a means of communicating with community members, particularly the most vulnerable; instead, prioritise one-to-one work by health and community workers to share information on ways to participate and to provide support for community members to help them on a journey of participation.

Recommendation 4:
To increase the number and variety of participation techniques in order to reach a wider range of community members

Recommendation 5:
To develop ways, such as the 'wheel of participation', to regularly monitor progress within community health and regeneration programmes in order to improve areas of the programme that may have limited participation and to keep participation on the organisational agenda.

9. 4. Through the Lens of Critical Theory

Critical theory proves useful in analysing why it was so challenging to make progress towards developing a fully functioning participation system. Habermas (1987) argues that the 'lifeworld' of communities has suffered a form of colonisation by institutions. This has resulted in a restriction of self-determination by those in the community and a de-coupling of organisations from the communicatively rational sphere of everyday life. Critical theory helps to explain the entrenched bureaucratic and hierarchical approaches that were identified during this study as a significant force in constraining the co-researchers' attempts in encouraging participation.

9.4.1. Empowering Front-line Workers

These hierarchical and bureaucratic structures have resulted in a lack of decision-making power and access to resources by those at the 'front line'. This has undermined the ability and enthusiasm of those working with communities to encourage participation. They are unable to respond to resident views as any suggested changes must be negotiated through hierarchical management structures and are often met with inflexibility. So while on paper the health and regeneration organisations appear keen to re-couple with the lifeworld, or community, in reality they are still working in traditional inflexible ways dominated by bureaucracy.

In response to this organisational disempowerment, health workers have traditionally focused instead on building a strong one-to-one relationship with their clients. While this may benefit the individual it is at the expense of seeing the 'bigger picture' of developing a service best able to meet the needs of the wider community. With these dual constraints of the traditional health worker approach and the lack of power within organisational structures, health workers may find it hard to recognise the value of participation as they do not see their role as one which should develop wider services. Even if this begins to change, they find no opportunity to influence within their organisations.

Recommendation 6

For health and regeneration organisations to devolve decision-making, including decisions on the deployment of resources to staff closer to the front-line.

Recommendation 7

For employers of health workers to ensure accessibility of training and support to help health workers develop their role in designing services and leading change.

9.4.2. Empathy with the Community

The concept of the colonisation of the lifeworld is helpful in understanding the relationship of the regeneration and health organisations with the community. However, the findings from this study show that some members of the organisation were less de-coupled from the lifeworld than others. Health workers who lived in the area and had developed through a journey of participation themselves displayed a greater sense of empathy with the community than those health workers from outside. These more empathetic health workers displayed greater enthusiasm for encouraging participation recognising a lack of confidence and self-esteem rather than merely blaming disengagement on apathy. Hence, it is these workers with a strong grounding in the community who offer the greatest potential for encouraging the development of a participation system within the programme.

Recommendation 8

For health and regeneration organisation to increase the recruitment of staff who originate from and are grounded in the communities with which they work.

9.4.3. Organisations Adapting to Communities

The findings of this study indicate that a coherent system for encouraging participation that includes effective communication and influence over decision-making is vital. However, a good system alone is not enough to encourage participation. Statutory organisations, such as those involved in the community health programme studied here, have become so firmly decoupled from the every-day life of community or lifeworld, that the communicative rationality of ideal speech – that is comprehensible, true, morally appropriate and sincerely stated – is now severely constrained.

However, this study has also identified a blurring of the boundaries between organisations and the community. The recruitment of front-line workers grounded in the community, who display greater levels of empathy towards their fellow community members, has the potential to be a positive force in the attempts of these organisations to encourage participation. However, while structures remain overly bureaucratic and hierarchical it seems unlikely that these front-line workers will develop the sense of empowerment needed to adapt and improve local services in line with the views and needs of their communities. To date there has been much emphasis on community members becoming immersed in and adapting to the ways of organisations. If there is to be any improvement in the ability of health and regeneration organisation in encouraging participation, then these organisations need to re-couple with their communities. Instead of asking communities to adapt to the ways of organisations, organisations must begin to adapt to the ways of communities.

9.5. Recommendations for Further Research

Recent years have seen an increasing number of heath and regeneration programmes advocating and attempting to encourage community participation. This provides an ideal opportunity for more robust and systematic research assessing which approaches to participation work best and for which groups of people within communities. The components identified in the participation system described here could helpfully form the basis for a clear and structured evaluation of health and regeneration programmes to asses which areas may be most challenging for such organisation to improve.

The literature reviewed for this study illustrated the dearth of studies exploring the impact of participation on the effectiveness, efficiency and sustainability as well as the impact of participating on the individual's health and well-being. Studies assessing such impacts would be helpful in adding substance to the arguments for encouraging participation and might therefore reduce the vulnerability of participation to the ideological whims of politicians.

Recommendation for Further Research

- *An increased emphasis on studies that systematically assess the effectiveness of participation approaches using a variety of quantitative, qualitative and action research approaches. The components of the 'participation system' may provide a helpful structure for such studies.*

- *Greater exploration of the impact of participation on health and regeneration schemes and on the participating individuals' health and well-being.*

- *More in-depth explorations, particularly through qualitative and action research approaches of the characteristics of, and factors which allow, health and regeneration organisations to successfully encourage participation.*

9.6. Recommendations for Health and Regeneration Schemes

1. *Health and regeneration organisations could utilise action research approaches more extensively in order to improve practice, offer a 'safe' space to encourage attitudinal change among staff and to develop greater understanding of the complexities within organisations.*

2. *For those within policy and practice development to recognise the importance of all components of the participation system including communication, participation techniques and mechanisms for ensuring those participating or results of their participation influence decisions taken.*

3. *To reduce the reliance on the written word as a means of communicating with community members, particularly the most vulnerable; instead, prioritise one-to-one work by health and community workers to share information on ways to participate and to provide support for community members to help them on a journey of participation.*

4. *To increase the number and variety of participation techniques in order to reach a wider range of community members*

5. *To develop ways, such as the 'wheel of participation', to monitor participation within community health and regeneration programmes in order to improve areas of the programme that may have limited participation and to keep participation on the organisational agenda.*

6. *For health and regeneration organisations to devolve decision-making, including decisions on the deployment of resources to staff closer to the front-line.*

7. *For employers of health workers to ensure accessibility of training and support to help health workers develop their role in designing services and leading change.*

8. *For health and regeneration organisation to increase the recruitment of staff who originate from and are grounded in the communities with which they work.*

Appendix 1: Table of Evidence of the Impact of Participation

Study	Topic	Methodology	Findings	Critique
Ahern, M., Hendryx, M. (2003) Social Capital and Trust in Providers. Social Science and medicine **57** p.1195-1203	To identify sources of trust in aspects of health care systems and the wider community in the US	Quantitative: Cross sectional study using data from 5 large databases/surveys Dependent variable was self-reported trust in doctors	The higher the social capital the higher the trust in Drs ($p<0.0001$) Those with increased trust in Drs were women, white, older, high income, small household, more education, better health, with health insurance	While they concludes that the level of social capital influences levels of trust people have in their doctors, this does not necessarily mean a causal link, could be that there are worse Drs in poorer areas.
Audit Commission (2004) An Early Progress Report on the New Deal for Communities Programme.	Early assessment of NDC Looks particularly at 4 areas: Involving community Operating processes Relations with partner bodies Design and delivery of sustainable results	Mixed Methods: Survey of local service delivery bodies for the 39 NDC partnerships (117 organisations responded) 5 case studies of NDCs 15 focus groups with residents board members and staff Review of national evaluation findings so far by Sheffield University	Ways residents have been involved: Representative boards. More than half of all board directors are residents (eval team) Local elections of board members Survey of residents views 65% of residents have heard of their NDC partnership 11% have participated in an NDC activity Many residents experiencing burn-out	The quantitative findings which form much of the study come from a survey of agencies not residents The report refers to engagement but does not differentiate between influence over decision making and mere consultation The results are not so clear when looking at actual survey results as most (32.5%) scored NDC a 3 (mid point of the liket scale used 1 good, 5 bad level of comm. engagement)
Baum, F., Bush, R., Modra, C. Murray, c. Cox, E., Alexander, K., Potter, R. (2000) Epidemiology of participation: an Australian community study. Journal of Epidemiology and Community Health. **54** p.414-423	To determine levels of participation (social and civic) in Adelaide in relation to demographic, socio-economic and health conditions	Quantitative: Cross-sectional postal self completed questionnaire to a random sample of 2542 respondents of 18+ from the electoral role in Australia	participation in social activities much higher than in civic activities There are a range of social and demographic variables that influence gender, age, physical and mental health, marital status, education, income Those in the bottom 1/3rd of all participation indices they called low-participators Women were less likely to be low-participators than men 21.6%of those with low-ed level were low-	Although they report that the area surveyed has a high number of ethnic groups for whom English is not a first language, they do not say whether the questionnaire was translated in to other languages and they do not use ethnicity as one of their variables.

			participators 17.6% of low-income were low participators 6.3% of high-income were l-p more divorced or separated were low participators of those with poor mental health 17.3% were low participators but those with good mental health, 12.2% were low participators those with poor physical health 16.9% were low- participators and with good physical health 10.3% were low-participators	
Cattel, V. (2001) Poor People, poor places and poor health: the mediating role of social networks and social capital. Social Science and Medicine vol **52** p.1501-1516	Looks at relationship between poverty and exclusion, neighbourhood and health/well-being by considering role of social capital	Qualitative: 2 Case studies of east London estates. Interviewed between 35-37 in each area plus 15 workers. Selected through participant observation, contacts and snowballing Used grounded theory	Those with more restricted networks were more likely to express feelings associated with negative health outcomes health problems experience by those in restricted networks were: anxiety, depression, headaches and stomach complaints There were some residents on both estates who described how becoming involved had changed their lives. Friendship networks had grown, they were enjoying life, and for many , their health and sense of well being improved also "Good health was attributed to being active or mixing with people." P.1511	Appears to present stronger evidence of a direct link between social capital and health. No reporting of disconfirming findings, does this mean their weren't any or that they haven't been explored?
Clover, K., Redman, S., Forbes, J., Sanson-Fisher, R., Callaghan, T. (1996) Two Sequential Randomized Trials of community Participation to Recruit Women for Mammographic Screening. Preventive Medicine **25** p.126-134	To see whether more women would be recruited for mammographic screening through mass media, comm. particip or GP involvement	Quantitative (RCT): Randomised trials in 2 towns Arm 1: mass media or community participation Arm 2: community participation or GP advice	In both towns in Arm 1 there was higher attendance (significant) at screening from comm. part (63% and 51%) than from mass media (34% and 34%) In one town in Arm 2 there was significantly higher attendance from GP (68%) than comm. part (51%) Other town it was not significant but still GP got higher % than comm. part	No details of the type of community participation used or the populations in that area, so hard to make a judgement about the appropriateness of their approach in encouraging participation.
Crawford, M., Rutter, D., Manley, C.,	To examine the effect of	Systematic Review: of English language	Unable to find any papers looking at the effects of involvement on use of services,	Their definition of participation based on individual as patient

Weaver, T., Bhui, K., Fulop, N., Tyrer, P. (2002) British Medical Journal **325** p1-5	involving patients in the planning and development of health care	papers between 1966-2000 of published and grey literature Found 42 papers that were relevant, most were case studies	quality of care, satisfaction and health of patients (outcomes) Effects on users – self esteem improved staff – rewarding services – new/improved information for patients, more accessible services, new services commissioned, changes/abandoned proposals to close hospitals staff attitude – more favourable to involving patients culture of organisation – more open to involving and more involvement initiatives concern that involvement used to legitimise difficult decisions one said it slowed down decision making process no consensus on which methods are most effective under different circumstances	or future patient Difficult to separate out causes of changes and link to participation “Absence of evidence should not be mistaken for an absence of effect” p.4 Review would have benefited from studies in the community development and health promotion fields.
Edmons, T. Taket, A. (2001) Community Led Regeneration: Experiences from London. Paper presented at the International Commuity Development Conference Rotorua, New Zealand Edmans & Taket	Community participation in a Community Health project	Qualitative: Case study based on participant observation, and some interviews.	Has had influence at the local level in : • building self-esteem • building trust • developing a greater understanding of local needs • identifying barriers to care • partnership working • creating local jobs • building capacity Strategies: capacity building and training need to be undertaken with/for community members as well as with/for the statutory and other agencies involved	No details given on the methodology of the case study.
Fitzpatrick, S., Hastings, A, and Kintrea, K. (2000) Youth Involvement in Urban Regeneration: hard lessons, future directions. Policy and Politics **28**:4 pp.493-	Consultation and representation processes for young people in area based regeneration initiatives in the UK	Qualitative: UK wide study 1997-98 Case studies of 12 area-based regeneration initiatives with a substantial youth focus Semi-structured	Consultation seen as good way to gather info on youths views and experiences Focus groups found to be best method of consultation and had impact in changing the focus of a bid in Leeds to more emphasis on sports and recreation also gave the youth sense of ownership over facilities	Lack of quotations in the text to fully express the views of young people, especially in terms of developing sense of ownership. Limited details of the case study methodology e.g. extent of immersion of researchers,

509		interviews with staff and youth. Focus groups with involved youth. 6 most informative case studies followed up 6 months later more interviews and focus groups but this time with youth not involved. Final visit for feedback seminar	All enthusiastic about youth conferences (one day events of 40-80 young people (but mainly recruited youth through schools and clubs only). But they only found one conference that had any impact in Shankhill where one strategic objective was changed to have a youth focus Joint management study found many difficulties as: only a few youth involved and not elected youth found it hard to speak out at meetings Youth control where young people own a project after developing it on their own or have delegated power – only found one example of this but was successful, but regeneration projects wary of this Youth forums: 9 of the 12 studies had them; separate from and parallel to adult structures, 30-80 young people no tangible impact on regeneration because of lack of representativeness, disconnected to decision making structures and lack of purpose	sampling of participants and analysis methods.
Hendryx, M., Ahern, M., Lourich, N. and McCurdy,A. (2002) Access to health care and Community Social Capital. Health Services Research **37**:1 p.85-101	Tests whether access to health care is related to level of social capital in the US	Quantitative: Cross-sectional surveys with self-reported data on access	People living in metropolitan areas with higher levels of social capital report fewer problems accessing health care	They argue this is because social capital improves community accountability structures which then means the community can put pressure on authorities to maintain accessible health care. But the methodology still does not allow causal links to be made. So the reason could just be that services are better funded in metropolitan areas.
House, J., Landis, K. Umberson, D. (1988) Social Relationships and Health. Science Vol **241** p.540-545	Searching for a causal link between lack of social relations and ill-health	Review: of research both epidemiological and experimental (on animals and humans)	Looks at evidence from: social support theory (Cassel and Cobb) who reviewed 30 studies and found social relationships protective of health prospective mortality studies and found	More work is still needed on process within social relationship and how they improve health. Still difficult to make a leap

			social network index (which included group affiliation) to be a 'significant predictor of mortality' experimental and quasi experimental research "clinical and laboratory data indicate that the presence of or physical contact with another person can modulate human cardiovascular activity and reactivity in general." P. 542	from animal experience to humans.
Johnson,L., Bauman, E., Moder, M., Serpe, R. (2002) Outcomes and Community Impact Programme. United Way San Diego County. Civic Solutions Report 25 www.unitedway-sd.org	To determine the extent that San Diego county residents participate in various types of neighbourhood groups	Quantitative: Telephone survey of 3650 in 2002 Stratified sampling by age, gender , income, education, location, race	Extent of participation: • 30% of respondents said they wanted to participate in a group to improve the quality of life in their neighbourhood • Significant difference in desire to participate: • by location • race: 29% of Hispanics wanted to participate, compared to AfroAm 41% • education: Only 25% of high school leavers, compared to 36% for post grads • age: more over 35s wanted to participation • income: over $20000 more likely to want to participate • marital status: more married want to participation • 17% of those interested in participating did Impact of participation (self rated): • 33% said they had an impact • 16% said they thought they had little or no impact • Those with less education thought they had a bigger impact	Study is limited by a low response rate: 1103 out of 3650 and by using a self-rated approach to determining the impact of participation
Kennedy, L. (2001) Community Involvement at what cost? Local appraisal of a pan-European promotion programme in low –income	Looked at trying to improve diet/nutrition and examined process of implementing health promotion	Action research: which included participatory appraisal of community nutrition and appraisal of process	The increased involvement of communities and the use of participatory appraisal helped to shift professional's way of working Led to great involvement of lay people Took some time to build community involvement because of conflicts with traditional ways of working.	Component of AR that looks at overall programme appraisal is not very clear, seems that it just centred around a SWOT analysis and some documentation analysis. Little detail of AR cycles and what

neighbourhoods. Health Promotion International vol **16** no. 1 p.35-45	theory of more community involvement			action helped move staff on. There is limited evidence to identify such major changes in organisational culture.
Kawachi, I. Kennedy, B. Lochner, K. Prothrow-Stith, D. (1997) Social Capital Income Inequality and Mortality. American Journal of Public Health **87**:9 p.1491-98	To see if income inequality leads to a reduction in social cohesion and disinvestments in social capital which in turn increase mortality	Quantitative: Cross-sectional study data from 39 US States Social Capital measured by: Membership of voluntary groups Levels of social trust Mortality data from 1990	• Income inequality is strongly correlated with group membership (p<0.01) and lack of trust (p<0.0001) • Social trust and group membership associated with total mortality as well as rates of death from coronary heart disease, infant mortality • The more people felt lack of trust the higher the mortality rate	Although they control for poverty as a possible confounder, this is still insufficient to really show a causal link between social capital and health.
Kawachi, I. Kennedy, B. Glass, R. (1999) social Capital and self-rated health: a contextual analysis. American Journal of Public Health **89**:8 p.1187-1193	Provides a contextual analysis of social capital and how it relates to individual self-rated health	Quantitative: Telephone survey of 39 US states on self-rated health and General Social Surveys for social capital indicators Measured social capital by trust and group membership	• Individual level factors like low income, low education , smoking were strongly associated with self-rated poor health • Controlled the above factors and still found that low social capital led to self-rated poor health • Odds ratio of 1:41 for poor health living in low social trust area compared to high social trust area (i.e. 4times more likely to have poor health in low social trust area) • In areas with low group membership 17.5% reported fair to poor health, in areas with high group membership this was only 11.6%	Regardless of doubt over a causal link, there is still little understanding of how processes works and thus how social capital can be built to improve health.
Lyons, M., Smuts, C., Stephens, A. (2001) Participation, Empowerment and Sustainability: (How) do the links work? Urban Studies **38**:8 p1233-1251	To look at the link between participation empowerment and sustainability in community development (building) projects in South Africa	Qualitative: Case Studies of 18 Community based organisation. Used workshops, interviews with community and staff, household interviews and census data	• Certain times when projects most vulnerable, i.e when cash arrives and there are 'individual jealousies and personal enrichment' and when move to a new buildings • empowerment of a community depends on commitment to empowering a large number of individuals and to spreading information , training and opportunity. • If hierarchical, can still be effective as long as consultation and representation of ideas put forward at grass-roots level	No details of analysis process given. Difficult to differentiate between findings and the authors own view points.

			appear to be carried out thoroughly, conscientiously and with regularity • Need clear allocation of responsibilities of leaders • Finds a link between the nature and extent of participation and the sustainability of development gains and empowerment • people need training in transferable skills then empowerment at 3 levels, personal, project and community • But not just training importance of local politics (must be transparent and accountable) and community structures (must have social mobility)	
Narayan, D. (1995) The Contribution of People's Participation: Evidence from 121 Rural Water Supply Projects. Environmentally sustainable Development Occasional Paper Series No.1 The World Bank, Washington, D.C	To determine the degree participation contributes to project effectiveness and which beneficiary and agency characteristics foster the process	Review: Studied evaluations of 121 completed rural water supply projects in 49 countries Quantitative analysis of outcomes and systematic qualitative analysis of the evaluations Used a collective action framework and did multivariate regression analysis to test the framework for causality Controlled for 18 determinants of outcomes	With participation there were significant improvements in: • good condition of water systems • overall economic benefits, • percentages of target population reached • environmental benefits • equality of access to facilities (less pronounced than those above) • fosters individual and community empowerment • build skills in the community • strengthened local organisations so they could do other development activities • But didn't get much participation of women Participation was the single most important determinant of overall quality of implementation The three factors which most helped participation were: • User investment in capital costs • Local ownership and control • Agency responsiveness to feedback	Methodological challenges of systematically comparing evaluations from such a wide range of programmes, using such a wide range of evaluation methods. There is no measure of how rigorous the original evaluations were.

			Three most common blocks to participation: • Unwillingness to give up control over implementation details • Lack of incentives for staff to support client orientation • Unwillingness to invest resources for building community capacity or social organisation to manage physical infrastructure	
Simpson, E and House, A. (2002) Involving Users in the delivery and evaluation of mental health services: systematic review British Medical Journal **325:** 7375 pp. 1265-1268	To identify evidence from on the effects of involving users in the delivery and evaluation of mental health services.	Systematic review: of English language articles published between Jan 1966 and Oct 2001 Selected RCTs and other comparative studies of involving users in the delivery or evaluation of mental health services	• Involving users as employees of mental health services led to clients having greater satisfaction with personal circumstances and less hospitalisation • Providers of services who had been trained by users had more positive attitudes toward users. • Only found studies of user involvement in providing services to other users did not find any where users were involved in the management, design and planning of services.	Summaries were done qualitatively rather than through meta-analysis due to variety of methods and outcomes in studies.
Schulz, A., Israel, B. Zimmerman, M. Checkoway, B. (1995) Empowerment as a multilevel construct: perceived control at individual, organisational and community levels. Health Education Research. **10**:3 p.309-327	Looking at relationship between organisational membership and perceived control at individual and community level	Quantitative: Testing models of multi-level perceived control using 12 questions within a large random sample survey in Detroit. 916 people were interviewed for the survey. Only blacks and whites used in analysis due to limited numbers of Asians/others	Members of voluntary organisations were more likely than non-members to: • think action taken would be effective • more likely to have taken action • more likely to believe they had an influence over their personal lives and community events even when they controlled other variables they found that Participants in voluntary organisations were older, better off and more educated than non members Members of voluntary organisations had higher levels of perceived control "Positive correlation between organisational participation and perceived individual and community control" p.323	Questionnaire did not define the term community, so could have been interpreted as geographic area or ethnic group or something else Point to literature which gives evidence to positive relationship between empowerment and improved health

Appendix 2: Table of Approaches to Participation

Study	Approach to Participation	Methodology	Findings	Critique
Alborz, A., Wilkin, D. and Smith, K (2002) Are primary care groups and trusts consulting local communities? Health and Social Care in the Community **10**:1 pp.20-27	Consultation Assess how PCG/Ts have informed and consulted local communities and the perceived impact of this consultation on decision-making	Mixed Methods: 15% of PCTs in England surveyed between Oct and Dec 2000 Survey using self-completion questionnaire for different PCG board members Based questionnaire on several exploratory interviews 63% response rate	81% of PCG/Ts had public involvement working groups but only 21 % of these had a designated budget and most budgets were £5000 or less Details of Participation Approaches: Consulting Community Heath Councils (CHC) (87%) Holding public meetings 75% Consulting local patient groups 67% Only 31% of chairs felt they were effective at consulting Only 14% of CHC representatives rated PCG/T consultation with the public as effective 87% said that local communities were largely unaware of the existence of PCG/Ts 70% commented on weakness of PCG/Ts in consulting 69% had written public involvement plans 77% said that consultation process had had little or no impact on clinical governance decisions 48%said consultation had little or no impact on local service delivery	Would have been helpful to track any direct influence of consultation results on the development of policy and practice, rather than measuring perceived impact of consultation
Anastacio, J., Gidley, B., Hart, L., Keith, M., Mayo, M. & Kowarzik, U. (2000) Reflecting Realities: Community participants' perspectives on involvement in area regeneration programmes. Joseph Rowntree Foundation	Consultation Representation	Mixed Methods: 4 case studies, 2 in London, Barnsley and Aston. Qualitative Interviews and focus groups with residents and workshops to feedback. No details of numbers/type of residents interviewed or how analysed Survey of 110 regeneration partnerships and programmes.	Where the community is seen as homogenous only the most powerful voices will be heard Too little time given for effective participation Not enough support and training Residents felt there was a gap between the rhetoric that demands community participation in area regeneration programmes and the realities of work on the ground.	More details on the methodology would be helpful. Unclear whether these are the views of residents already involved or a broader cross-section.

Anderson, W., Florin, D., Involving the Public – One of Many Priorities: a survey of public involvement in London's Primary Care Groups. Kings Fund 2000	Consultation And some lay representation on Boards	Quantitative: Self-complete postal surveys, one to lay members and one to chief executives of 66 PCGs in London.	Most of the public participation carried out by PCGs was communication and consultation Low resources available for participation Increase in corporate approaches to participation Chief execs and lay members do give a high priority to participation, but just one of many high priorities	More in depth case studies could have shed light on the extent of impact of lay members and of results of consultation.
Attree, P. (2004) It was like my little acorn, and it's going to grow into a big tree': Qualitative study of a community support project. Health and Social Care in the Community **12** (2) 155-161	Communication to the most isolated in the community	Qualitative: study in a SureStart programme in the NW. Used focus groups and semi structured interviews with staff, community support workers (volunteers) and managers	Use of support workers from the community helped in encouraging participation even of hard to reach community support workers still need structured links with health professionals to address serious issues that come up with families clarity on differing roles between community support workers and	Sees participation as the community support workers who participate to help other families in the area. Would have been strengthened by interviewing residents. Also no clear definition of 'hard-to-reach' and no attempts to find their views on the values of the support workers. In fact did interview any residents, except support workers
Bagley, C., Ackerley, C. and Rattray, J. (2004) Social Exclusion, Sure Start and Organisational social capital: evaluating inter-disciplinary multi-agency working in an education and health work programme. Journal of Education Policy. 19:5 pp 595-607	Representatives on a Sure Start Board	Qualitative: Analysis of documentation, observation of meetings and 32 semi structured interviews with members of the interdisciplinary team implementing SureStart. Analysis conducted through open coding from grounded theory.	Programme managers able to fit national targets to local contexts, but pressures to conform to national targets are increasing Parental majority on partnership board Non-hierarchical approach to management Sharing information between disciplines Single building helped disciplines to work together Because of all above, they were able to involve representatives in design and deliver and make changes based on client feedback.	No methods to hear parents' views. Does not have outcome data to see real effects of all the positive partnership working.
Barnes, M. (1999) Users as Citizens: collective Action and the Local Governance of Welfare. Social Policy and	Representation through user groups	Qualitative: The methods are not described in any detail, however they interviewed groups of disabled people and mental health service users, they	Officials see user groups as unrepresentative Distinguishes between groups linked by identity and by interest	Difficult to critique as so few details of the methods are given.

Administration **33**:1 p.73-90		also interviewed local officials	User groups may wish to influence the public as well as services	
Burton, P., Croft, J., Hastings, A., Slater, T., Goodlad, R., Abbott, J. and Macdonald, G. (2004) What works in community involvement in area-based initiatives? A systematic review of the literature. Home Office Report 53/04, Home Office.	Consultation and representation	Systematic Review: of 26 studies to identify what works, what does not, what is promising and what is unknown Includes: Studies of the impact of community involvement on area based initiatives and broader studies on such initiatives published after 1980, in English,	Identifies a lack of detail in presenting methodology in much of the literature on area based initiatives Finds and increase in community involvement in policy, but not in practice Identifies the importance of local context in influencing effectiveness of participation Identifies a range of approaches which broadly fall within consultation and representation. Finds little credibility given to more alternative methods such as drama. Identifies range of difficulties with representatives, i.e. high expectations, lack of representativeness, poor structures Finds flexibility and variety of approaches to be most effective Identifies a lack of evaluation of participation strategies within programmes	Lack of inclusion of health related search engines such as pub med, web of knowledge. Presented in a narrative style without systematic discussion of research approaches of each study.
Cornwall, A., Lall, P., Kennedy, K. and Owen, F. (2003) Putting Partnership into Practice: participatory well-being assessment on a south London housing estate. Health Expectations. **6** pp.30-43	Consultation that leads into critical engagement and action planning.	Mixed Methods: Participatory well-being assessment in a housing estate. Roughly 10% of the residents (500) were involved in the study. Which included training up 30 residents and staff in participatory techniques and then conducting PLA exercises such as social mapping, body mapping, timelines etc with residents. Residents were selected through social venues and through networks of the trained residents. Culminated in an action planning workshop where	Built new relationships between staff and residents Created a 'vehicle for change' as residents became involved in health and well-being project development Greater opportunity for service responsiveness and citizen involvement Findings of the survey conducted a year after the exercise 87.5% of them felt the experience had changed they way they work. Approach taken up and used in 3 other London boroughs.	Lack of details of the final survey are given Few quotations from community members are given which does little to strengthen some of the claims made for the approach – although the final survey helps.

		staff and residents worked together. Conducted survey of those involved one year after		
Dinham, A. (2005) Empowered or over-powered? The real experiences of local participation in the UK's New Deal for Communities. Community Development Journal. 40:3 pp.301-312	Resident representation in an NDC in London	Qualitative: (although doesn't state this explicitly) interviews with 30 residents, including professionals and non-professionals, and community members engaged and not engaged in June 2001 and July 2003	Elections only draw in people who are already very active in the community Elections seen as main way for people to participate People preferred less formal groups Other problems Timescales for engagement too short NDC internal communications poor Not using local staff but external consultants and outside professionals Lack of training and support Community itself divided and characterised by back-biting and no community development style initiatives to overcome this.	No description of the analysis or sampling approach is given Valuable that both the engaged and unengaged residents were interviewed.
Foley, P. & Martin, S. (2000) A New Deal for the Community? Public Participation in Regeneration and Local Service Delivery. Policy and Politics **28**:4 pp.479-491	Representation	Quantitative: 30 community representatives managing of Single Regeneration Budget (SRB) programmes and 50 policy makers Both groups were given the same questionnaire to fill out in groups at a conference.	Both groups thought community representatives had detailed knowledge of their areas and of local needs Neither believed that community representatives were independent Policy makers thought that the involvement of community representatives made programmes more inclusive and legitimate. Community representatives did not agree Both groups were concerned about skills, time and resources for community representatives Both were concerned about the dominance of a few community members	Relatively small samples and limited questionnaire. More details and in-depth understanding could have been developed with qualitative interviews to complement the questionnaire.
Harrison, S., Dowswell, G., Milewa, T. Heywood, P. Tovey, P. and Ahmad, W. in Farrell (2004) Patient and Public Involvement in	Mainly consultation, but some representation.	Qualitative: Farell's report is a synthesis of 12 research projects looking at patient and public involvement. Harrison et al.'s study gives the most detail of the mechanisms of participation.	Identified problems in consulting the healthy, minority ethnic groups. Poorer people young adults and patients groups without established local advocacy Nationally, 30% of PCG/PCTs could by early 2000 cite involvement activities that had resulted in demonstrable changes in	Lack of clarity and detail about exactly which approaches to participation have been tired. No detail on what forms of consultation were more likely to influence policy and practice.

Health: The evidence for Policy Implementation. A summary of the results of the Health in Partnership Research Programme. DoH.		Study was conducted nationally from 1999 to 2001. They used telephone interviews with randomly selected sample of half the PCTs in London Followed by 'scoping' interviews with 34 representatives from community organisations and the statutory sector nationally. Followed by 68 focused interviews with stakeholders in 3 health authorities and then 44 telephone interviews	policies plans or health care provision Local history of multi-agency work around community involvement and local authority experience with drive and commitment of resources more likely to have effective consultation processes.	
Jewkes, R. Murcott, A. (1998) Community Representatives: Representing the Community? Social Science and Medicine Vol **46**:7 p.843-858	Explores how community representatives are selected	Qualitative: Ethnographic case study of 4 Healthy Cities initiatives in SE England. 50 in-depths interviews with health authorities, local government and voluntary sector. Also non participant observation and documentation review	Community representatives were all selected from local voluntary organisations and not directly from community Most community representatives felt they should have a lobbying role and not be part of state sector like councillors are (although they're elected) Staff selected 'representatives' for their knowledge of the language of community health Ability to communicate in English Use of an office with a phone, as staff didn't like using home numbers.	Limited by the lack of interviews/survey of community members to discover their perspectives on community representatives.
Jordan, J., Dowswell, T., Harrison, S. Lilford, R. and Mort, M. (1998) Health Needs Assessment: Whose Priorities? Listening to users and the public. BMJ **316** pp.1668-1670	Consultation	Review: of approaches to user and public participation Does not describe process for selection of papers	Finds that health authorities have increased consultation but quality poor, with most doing one off exercises Professionals decide whether to make use of consultation data or not Changes to the organisation and funding of primary care are vital if effective involvement is to be sustained	Very limited by the lack of justification for the articles included in the paper.
Lenaghan, J. (1999)	Deliberative	Qualitative: An evaluation of	People can participation meaningfully in	Limited descriptions of how

Involving the Public in Rationing Decisions. The experience of Citizens Juries. Health Policy. 49 pp.45-61	Consultation through Citizens' Juries	8 pilot citizens' juries. Jurors were asked to give their views through qualitative interviews on the process of the jury. Review of documentation from the pilot juries.	decisions about the allocation of finite resources for health care This depends on the nature of the question put to the jury, the development of the agenda and the kind of information they have access to. The majority felt that the public should be involved in rationing decisions.	the qualitative interviews were conducted among the jurors. No information about which jurors were interviewed or what questions they were asked or how interviews and documentation was analysed.
Litva, A. Coast, J. Donovan, J. Eyles, J. Shepherd, M. Tacchi, J. Abelson, J. Morgan, K. (2002) 'The Public is too subjective': public involvement at different levels of health-care decision making Social Science and Medicine **54**:12 p.1825-1837	To look at public preferences for being involved in particular types of rationing decisions	Qualitative: 8 focus groups of 57 informants; four from randomly selected members of the public and four from health and non health organisations	Variations in willingness to be involved Strong desire from all to be involved at system (location of services) and programme levels (funding prioritisation through consultation, without responsibility for decisions but with the guarantee that their contribution would be heard and that decisions taken following consultation would be explained Less willing to be involved at individual level Demand for more information	Qualitative data is displayed as percentage which appears misleading.
Marrow, G. and Malin, N. (2004) Parents and professionals Working together: turning the rhetoric into reality. Early Years. **24**:2 pp.163-177	Recurrent participation of parents who are members of a SureStart parents' committee	Qualitative: 6 small focus groups with staff and 2 sessions with the parents committee No description of the analysis process	Committee met once a week supported by 2 staff. Had grown over a two year period from one to 18 members Committee was not established with a defined purpose For parents the motivation was to get more into the area for children and to make friends and have support of other parents Parents cited the ways being on the committee had built their skills and confidence Eventually parents took on more decision-making organising events with their own budgets Was a new way of working for most of the professionals and presented personal and agency challenges. i.e. difficult boundaries between personal relationship	The methodology is limited by the lack of individual interviews with parents. Potentially focus groups may only facilitate the more confident to speak. Interviews with parents that may have dropped out or would not consider coming to the committee would add strength to the study. Limited details of the sort of parents that join the committee and how representative they are. More details on how the the committee was started what attracted residents to it and how much influence they have would further strengthen

			with parents and professional Professionals felt this had reduced the 'us and them' attitude	the study.
Martin, S. and Boaz, A. 2000 Public Money and Management April-June 47-53	Consultation	Mixed Methods: Evaluation of two pilot initiatives, Best Value and Better Government for Older People. Includes surveys of residents in the areas	• BV survey showed that 78% wanted council to find out what they wanted. • But only 21% wanted more say. • Most wanted passive consultation, • 6% would be part of citizens panel and • 3% in citizens juries	The only details given of the methods used in the evaluation are the survey of residents and no information is provided about who was surveyed, and how they were selected.
McInroy, N. (2000) Urban Regeneration and Public Space: The Story of an Urban Park. Space and Polity 4:1 pp.23-40	Representation	Qualitative: Case study of an urban park regeneration programme in Scotland. Observation at council meetings Interviews with regeneration and community actors Review of documentation	• Local community groups were unrepresentative of their communities • Community groups offered the local authorities a veneer of public participation which was used mainly for public relations purposes • All groups, particularly the young were not included and hence there are tensions within the resultant design and function of the park.	Few details of the interviews conducted, such as who was interviewed, how they were sampled or how data was analysed. Lack of data or quotations presented on community perspectives of the park after the regeneration initiative leading to the impression that it is could be only the author's view that the park is unsatisfactory.
O'Donovan, O. (2000) Re-theorizing the interactive state: reflections on a popular participatory initiative in Ireland. Community Development Journal. **35**:3 pp.224-232	Representation	Qualitative: Ethnographic study of the process of participation of representatives in a government consultation exercise. Observation of meetings and Interviews with women's representatives	• The women's representatives were able to have some influence on the consultation conducted • They went along with the dominant professional views of health during meetings	Limited details of the number of interviews or meetings observed. No details of the analysis process.
Perrons, D. and Skyers, S. (2003) Empowerment through Participation? Conceptual Explorations and a Case Study. International Journal	Representation: Looks at participation in Hackney NDC	Qualitative: Case Study with qualitative interviews with 45 members of the board, the Trust local tenants and residents and key operators in regeneration some were done by video.	• Problems of representation, residents voting for board members who are 'one of them' as need to understand the language of officialdom • In light of this NDC has tried to take a more flexible approach using "door-to-door surveys, group discussions, neighbourhood meetings and formal	The analysis process is not described beyond saying that ethnograph was used.

of Urban and Regional Research. **27**:2 pp. 265-85			and informal local partnership forums. - Suggest that "extending governance may simultaneously weaken local democracy by prioritising the interests of those who have the time or inclination to be involved.	
Pickard, S. and Smith, K. (2001) A 'Third Way' for lay involvement: what evidence so far? Health Expectations 4 pp170-179	Representation : lay board member involvement in PCG decision – making and the engagement of the PCG with the wider public	Mixed Methods: Uses data from an annual tracker survey of a sample (15%) of PCGs stratified by region between Sept and Dec 1999. Interviews, postal questionnaires sent to lay members and a documentation review.	- Roles of lay members ill-defined - In the majority of cases their involvement in key decision-making was low, but many were happy with this - Only 2% had been elected to the post, most replied to newspaper ads - Training provided was variable - Felt they only had a moderate influence on decisions taken - Many lay members had come from Community Health Councils - Engagement with the wider public took usual forms, newspapers info to voluntary groups - 82%had not produced patient questionnaires and comment forms and 64% had not held public meetings 70% had no plans to consult patient groups - Over half of lay members believed attempts to consult had not occurred or been ineffective, but felt they were committed to doing it in the future. - More info giving than consultation	The study is constraint by the fact that the survey ws conducted after only 6 months of PCG/PCT establishment.
Purdue, D., Razzaque, K. Hambleton, R. Stewart, M., Huxham, C. and Vangen, S. (2000) Community Leadership in Area Regeneration. Joseph Rowntree Foundation.	Representation	Qualitative: 9 Case studies of SRB schemes in UK. Studies were chosen to display a range of characteristics. Each case study involved: - Documentation review - Individual interviews with community leaders and	- Contribution of community leaders is undervalued - Other regeneration partners do not always trust community leaders - Requires much commitment, balancing conflicts and fighting off burnout - Representativeness and accountability of community leaders is	The study was limited by a lack of Interviews with partner organisations and other community members (not leaders) who could have shed light on perceptions and influence of leaders

		secondary leaders • 88 interviews were held, 42 were women and 22 from ethnic minorities Group discussions with leaders	limited by patterns of social division • Tensions between old and new leaders	
Robert, G., Hardacre, J. Locock, L. Bate, P. and Glasby, J. (2003) Redesigning mental health services: lessons on user involvement from Mental Health Collaborative. Health Expectations. 6 pp.60-71	User representation	Action Research/Qualitative: • Action Research lasting 6 months of six case studies. Case studies were randomly selected. Each case site was visited at least twice. 65 semi-structured interviews with project managers, team members user representatives. Some face to face and some telephone • Observation of team meetings in six mental health trusts • Used content analysis by theme cross-checked by multiple researchers	• Process mapping when conducted jointly by staff and user representatives led to learning by both groups • Challenging for those professionals providing care and engaging with the same users in meetings • Service users lacked confidence to get involved • Users were not seen as representative of the wider client group • Some changes to service were made i.e. changes to documentation, signs within clinics and involvement mechanisms	Action research used to describe a process of stages of feedback to the Collaborative. It does not refer to a more participatory design using co-researchers.
Shaw, K. and Davidson, G. (2002) community Elections for Regeneration Partnerships: A new Deal for Local Democracy. Local Government Studies. 28:2 pp.1-15	Representation: elections	Qualitative: Review of NDC experiences of elections and more detailed study on one NDC area in Newcastle West Gate using documentation review	• Elections were held on request of the 'community' • Believed it would enhance legitimacy of the representatives on the Board, have an educative role, allow direct representation of different areas, • Turn out was higher in each area than for local government polls i.e. 41% in NDC in Newcastle compared to 24% in local government polls	Limited details of how information on the case study was collected.
Wood, M. (2002) Resident Participation in urban and community renewal. Australian Housing	Representation: Looked at: • models of renewal • rationale for	Qualitative: Case studies in six neighbourhoods in 3 regions of Australia Interviews with regeneration	Reasons for participation: • managerial benefits i.e. efficiency savings • citizenship right to influence decisions • Participation strategies used:	Few details of the in depth nature of the case studies.

and Urban Research Institute.	participation • models and practices of participation • barriers to participation • good practice	stakeholders Focus groups with residents	• forums to represent the views of communities, representativeness varied • consultation exercises • only two of the localities had a direct mechanism for residents views to feed into decision making processes Barriers to participation: • poverty and feelings of stigmatisation • limited coordination of renewal projects • raised expectations that had not been me • previous poor experiences • feeling professionals failed to listen • conflict at community meetings	
Woodward, V. (2000) Community engagement with the State: a case study of Plymouth Hoe Citizen's Jury. Community Development Journal. 35:3 pp.233-244	Deliberative consultation through citizens juries	Qualitative: Case study of a citizens' jury using participant observation interviews with each member of the jury.	• Jurors increased their understanding of political processes and possibilities for engagement • But the short term nature of the jury means there is limited strategic and resourced interventions in light of the jury	Very few details of the methodology, i.e. how was the experience of the jury recorded, focus of the interviews, analysis process. Not helped by the lack of clear presentation of findings within the article.

Appendix 3 Information Sheet for Participants

Title of the research: **Participation in a Community Health Project**

You are invited to participate in a research study. The information in this leaflet aims to give you all the details you need about the study so that you can decide whether you want to take part or not. If there is anything that is not clear or anything else you want to know please ask the project worker who has given this to you or contact the main researcher, Helen Elsey – the contact details are given at the end of this pamphlet. Thank you for taking the time to read this.

Who are the researchers?
The research team is made up of project workers from New Deal for Communities (NDC) [redacted] and a research student, Helen Elsey, from the School of Nursing and Midwifery at Southampton University.

Why are we doing the study?
[redacted] residents and NDC project staff are concerned that only a few residents are actively involved in the health projects in [redacted]. This research has been designed to look at new ways of encouraging participation and assessing how effective these new approaches are. We hope that the research will improve the level and quality of residents' participation in the NDC health projects.

Why me?
Our research looks at one of the NDC health projects – the [redacted], which aims to improve the support available to parents and guardians with children and young people under 17 years old. This means that we are interested in talking to residents in [redacted] who are looking after children or young people in this age range. We are very interested in hearing about your experiences and views so that we can try and improve the support provided to parents and guardians in [redacted].

Do I have to take part?
No, participating in this study is completely voluntary. It is up to you to decide whether you would like to participate or not. If you do decide to take part, you are still free to withdraw at any time and without giving any reason. If you decide not to take part or to withdraw, this will in no way affect the support you are given in future by the [redacted] or other NDC projects.

What will happen if I do take part?
If you do decide to take part you will be asked to sign the attached consent form. Then a researcher will make an appointment with you to ask you some questions about your experiences of becoming involved, or not in the [redacted]. In order to capture exactly what you say, the researcher will ask you if you mind them recording the interview. You are free to say 'no' if you wish, however all the tapes made during the research will be kept locked away for 15 years and then destroyed once they have been analysed (in accordance with the Data Protection Act) and your name will not be linked to the typed-up version of the interview. Your experiences and views will then be discussed by the [redacted] – during these discussions your identity will remain confidential. The [redacted] will use the information that you and others provide to reshape the way they work to try and encourage more effective participation in the project. It is possible that one of the research team will come back to you in a few months time to see if you have noticed any changes in the way [redacted] works and to get further experiences, views and ideas from you. Again, you are free to say you do not wish to participate in any further interviews. We plan to carry out the study from October 2003 to July 2005.

What are the possible disadvantages of taking part?
The main disadvantage is that we will take up some of your time. There is also a possibility that the interview will cover some issues that you may feel are sensitive, such as your feelings about your support workers.

What are the possible benefits?

We hope that this study will help the [redacted] to become a project where the views and experiences of [redacted] residents guide the development of the project and shape the ways that project workers relate to residents.

The findings of the research will be shared with other projects in [redacted] and with community health projects up and down the country. This will hopefully influence others to improve the level and quality of participation within their work.

How can I find out the results of the research?
Regular updates on the progress of the research will be given at the Family Forum which you are invited to attend. For more details contact the Project leader, [redacted], her phone number is given at the end of this leaflet. We plan to finish the research in July 2005, once all the findings have been discussed and analysed, we will organise a meeting to present our findings to [redacted] residents and project workers. This is your chance to find out more about the final results of the study and to question any of the findings.

Is it confidential?
Yes. All information gathered by the research team will not be linked to you by name, address or any other way of identifying you. All recordings that are made of interviews, once they have been typed-up and analysed, will be stored for 15 years and then destroyed (in accordance with the Data Protection Act). During discussions among the research team, the team members will not refer to anyone by name. However, it is possible that due to their strong links and knowledge of the community in [redacted], that it becomes obvious to other members of the research team, who you are. All the meetings held between the research team are also strictly confidential and the team members will not talk about anybody who has participated in the study outside of the group. So even if your identity becomes obvious to others in the research team, they will not discuss your details outside of the team meetings.

What will happen to the results of the research?
The results of the research will be used immediately by the [redacted] to try to improve the way they work. This process will last for the entire year of the research project, October 2003 to October 2004.

Once the main part of the project has finished, the research student will write the whole research project up for a PhD dissertation. It is also hoped that the research student and others in the research team will be able to share the experiences of the research with others, through journal articles or through local and national meetings.

Who is organising and funding the research?
The research student is funded by the Southampton City Primary Care Trust. The other members of the research team from the [redacted] are funded by NDC. In the early stages of the research, the research student has done much of the planning and design of the study, this has been developed through close collaboration with residents and project workers involved in the NDC health projects.

Who has reviewed the study?
The study has been reviewed by the South and West Local Research Ethics Committee. Contact: Clair Wilkinson, Research Ethics Administrator, Southampton and SW Hants Joint Research Ethics Committee, Trust Management offices, Mail-point 18, Southampton General Hospital, Tremona Road, Southampton, SO16 6YD. Tel: 02380 704912

More information about the research is available from Helen Elsey.

Contacts

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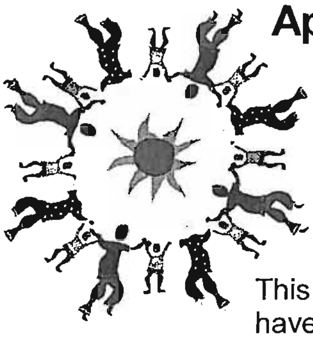
Research Student
School of Nursing and Midwifery



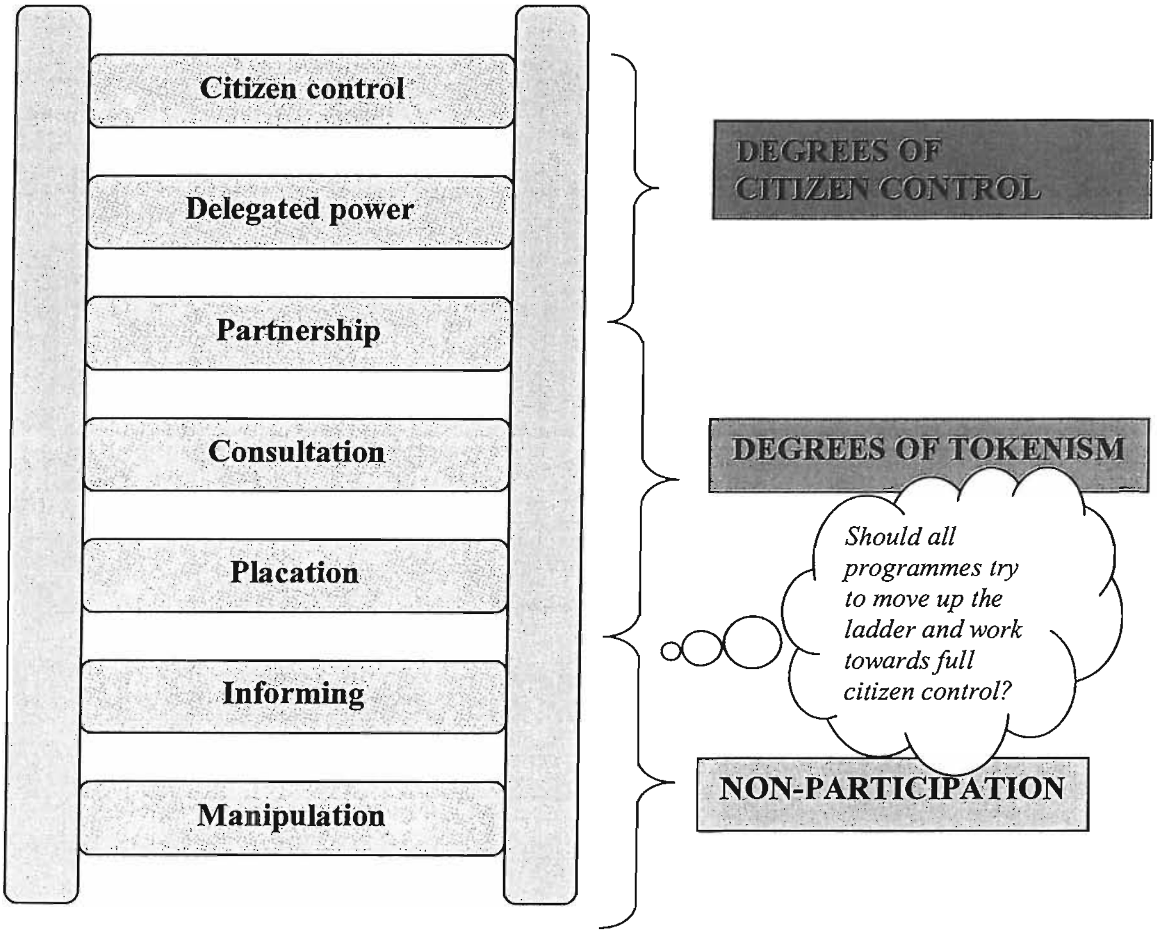
Appendix 4: Participation Brief I

Participation: What Does It Mean and What's Been Tried?

This is the first in a series of briefings looking at participation. They have been produced as part of an action-research project being run by NDC's [redacted] Programme and funded by [redacted] Primary Care Trust. The action-research group are trying out different ways of increasing participation within the work of the [redacted] Programme. As the group find out more about participation and what works in [redacted]!, we will produce further briefings to share our experiences with others working in NDC and beyond. This first paper is a summary of research and thinking on participation. We hope it will help you to think about community participation in your own work.

What Is Participation?

Many people have pointed out how there are different levels of participation. One of the first to do this was Arnstein. She developed a ladder of participation in 1969. The main elements of her ladder are shown below:



Why Do We Want Participation?

While for many involved in community development and health, there is a strong feeling that encouraging participation is the best way to work with communities, it is still important to be clear about ***why*** we feel this is a good idea. Understanding why we are encouraging participation influences the approaches that a programme will use. Some of the main arguments for encouraging participation are:

1. Participation is good for our health

Much research has been done in the US to show how our level of involvement can influence our health and well-being. For example, the research shows that where people had strong social networks, joined community groups and organisations, their health, well-being and even life expectancy were better than those living in areas with weaker social networks and low community participation.

In areas with low group membership, 17.5% reported fair or poor health, compared to only 11% in areas with high group membership. (Kawachi et.al. 1999)

2. Participation is good for community development and health programmes

In the last few years regeneration programmes, like NDC, have emphasised the importance of community participation in ensuring that programmes meet their goals effectively and that the changes these programmes bring can be sustained over time. Unfortunately, not many programmes have clearly evaluated the effect that community participation has had on achieving their key goals. However, many programmes that have not involved the community have failed or if they have had success, this success has not continued after the end of the programme. While there are not many evaluations of the effects of participation in the UK, elsewhere in the world there have been more systematic studies that have found participatory programmes to be more effective and have more long-term benefits.

One study looked at evaluations of 121 projects in 49 countries; projects that were highly participatory were 27 times more effective at achieving their goals than those with low levels of participation (Narayan, 1995).

Several studies have found that greater levels of community participation have not only helped to build individual's skills and abilities but have also strengthened organisations. In particular, greater community participation has helped programme staff to value the knowledge of local people and build stronger relationships with the communities they work with.

3. Participation is a right – we all deserve to be empowered

Feeling a sense of control over your own life and being able to understand and influence things that happen in your community is a positive and empowering experience. Being empowered in this way is beneficial not only for our own health but also for how we feel about the community we live in. Increasingly the United Nations and other international bodies emphasise that it is our right to be fully involved and able to influence what affects our lives.

"Every citizen shall have the right and opportunity to take part in the conduct of public affairs, directly or through freely chosen representatives." (International Covenant on Civil and Political Rights, Article 25)

> *Why do you want to encourage community participation in your programme? Is it because you think it benefits the individual? Or the whole programme? Or that it is everyone's right? How do these different reasons affect the way you might encourage participation in your programme?*

What Has Been Tried And What Lessons Have We Learnt?

There are some pretty convincing arguments for encouraging participation in community health and development programmes. However, the difficult question is how to encourage community participation in practice. Here are some of the strategies that have been tried and some of the challenges they encounter:

1. Passive Consultation

Surveys and focus groups have been used extensively by regeneration programmes and local authorities. They are a very straightforward and relatively quick way of finding out what people's needs are or what they think about various policy or programme options.

Consultation: Some of the Challenges

- Surveys are structured on the issues that the local authority or agencies see as important; these may be different from the issues that are important to communities. The consultation may just produce **an echo of agency thinking** rather than true community perceptions.
- In a review by the Joseph Rowntree Foundation (2000) of consultations in urban regeneration projects residents felt that consultation exercises were **rarely given enough time or support** to be effective
- **'Consultation fatigue'** is common where many programmes all want to assess community needs. Greater coordination between different programmes can help in designing one consultation exercise that covers many issues.
- Consultation with no subsequent changes is frustrating and disempowering; **feedback** about what is going to change because of the consultation and also, what will not change is vitally important.

2. Critical Engagement

Several methods can be used to facilitate people to think through the issues that affect them in more depth. Some of these are:

(a) **Citizen's Juries**: These normally involved about 12 or 16 'jurors' who deliberate over a key policy or planning question. They can draw on the advice of 'witnesses' who are experts on particular aspects of the question. They are chosen to be broadly representative of their community.

Citizen's Juries: Some Challenges

- Facilitation needs to be tight enough to focus the debate without stifling the jurors' free-thinking
- Jurors need enough information to engage in the debate effectively
- It is very difficult to find 12 or 16 people who can adequately represent all the perspectives of their community
- Evaluations of citizen's juries have shown that they have had some influence on the thinking of agencies or local authorities; however this was mainly in adding weight to issues already on the authorities' agenda (Lenaghan, 1999)

(b) **Participatory Techniques**: These techniques have been used in developing countries for many years and are beginning to find their way into UK community health and regeneration work. The acronyms that are used to describe them have evolved over time, and you may come across them as PRA (Participatory Rural Appraisal) or PLA (Participatory Learning and Action). They include a huge range of diagrams, charts, maps and matrixes that groups can develop themselves to better understand the issues and problems in their own community. They can be used for any issue – health, environment, infrastructure planning, social and organisational development. They are a good way of starting off a participatory programme, keeping the work focused on the needs of the community and then facilitating the community to evaluating the programmes' progress.

PRA/PLA: Some Challenges

- They are very dependent on the skill of the facilitator to involve all the group members without dominating the debate themselves
- When they are not linked into a participatory programme of action these approaches can raise expectations and lead to frustration

3. Representation

Increasingly members of the public are becoming lay representatives on committees and boards. There are great variations in how such committees are structured and the amount of influence lay members can have. While research in this area is limited, what is available has often found that the amount of influence lay members have over decisions is very limited.

> "The mere establishment of structures like committees effectively fails to address imbalances in power between providers and the supposedly empowered users of services." (Cornwall and Gaventa 2001 p.10)

In the UK and Australia, studies of Youth Forums – where young people can debate issues of importance to them and their communities – have found very few that are linked into decision-making structures. Inevitably these forums become a talking-shop with no influence over changes at community level. Studies in South Africa have found the importance of not only training and support for local people who want to join committees and structures, but also for programme staff to help them make the transition from provider to partner.

Many studies that have looked at community committees, organisations and structures have found that people who get involved are normally the most confident, better-off, better-educated people in the community (Schulz, 1995; Baum, 2000; Abelson 2001; Hogg, 2001). All these studies raise questions about how those that do get involved can be truly representative of their wider community.

Conclusions

While there may be no easy answers in encouraging participation, the studies point to some important learning points:

- It's important to be clear about *why* you want participation in your programme – this helps when working out how you are going to encourage participation in practice.

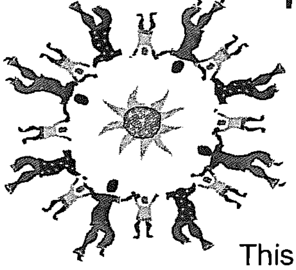
- Consultation, especially as a one-off may only ask the questions institutions want answering and can be frustrating for all involved, especially residents

- Forums and methods that help people to think critically about issues, like citizen's juries, youth forums and participatory methods have to be facilitated well and feed directly into decision-making structures to have any impact

- Setting-up committees with resident representatives may only hear what the most empowered people have to say; the people you may most want to reach are unlikely to get involved in this way.

- A mixture of different techniques may be the best way of reaching a wider number of people. But it is still important to be clear whether you just want their views or whether you want to set up ways of empowering people to take greater control over their own lives and the future of their community.

What do you think about what you have read? We would welcome any ideas or experiences that you have on community participation – if you would like to share these with us or find out more about any of the participation methods described here, the group can be contacted through Helen Elsey on ☎ 023 80 598 203 h.elsey@soton.ac.uk or [redacted]



Appendix 5: Participation Brief II: Reconnaissance Phase Findings

Encouraging Participation: Constraints and Experiences

This is the second in a series of brief papers looking at participation. They have been produced as part of an action-research project being run by New Deal for Communities' (NDC) [redacted] Programme and funded by [redacted] Primary Care Trust. The action-research group are trying out different ways of increasing participation within the work of the [redacted] Programme. The group interviewed staff and residents in [redacted] during April – July 2004 to:

- understand the experiences residents have had of trying to participate in activities and decision making in [redacted]
- to find out the lessons that have been learnt by NDC and partner agencies trying to encourage resident participation

Who did we speak to?

The action-research group interviewed staff with experience of participation and [redacted] residents with children from 0-17; the interviews were recorded or detailed notes were taken and typed up.

We carried out:

- 7 interviews with staff from NDC, [redacted] Primary Care Trust, the City Council, a local school and voluntary organisation
- 15 questionnaire interviews with [redacted] residents. The residents we spoke to were all female and the majority were aged 25 or younger
- meetings with the [redacted] Programme Sub-group, the Health Working Group, midwives and residents involved in a stay-and-play group

It is important to say that this small study cannot give a representative view of what all those living and working in [redacted] think about participation. Instead the study gives an indication of some of the main issues and will guide the action-research group as we try out different approaches for encouraging participation in our work.

What did we find out?

1. The Meaning of Participation

For the majority of those working with NDC and other agencies, they saw participation as a spectrum from fairly passive consultation through to very active involvement in decision-making bodies:

> ***"There has been a very structured idea of participation which involves people getting on a committee. I think that has changed a lot over the last couple of years and it has been recognised that even low level participation, a quick bit of consultation is as important." (Interview with agency worker)***

The residents we spoke to were more likely to interpret participation as getting involved in a support group or activity organised by one of the statutory or voluntary organisations. Few of those interviewed had considered participating in the management and decision-making within the [redacted] Programme.

2. Key Constraints to Participation

From Residents: Many of the residents had different reasons for not participating in groups in [redacted] but some common themes were a lack of information, the timings of meetings, concerns about mixing with others and a feeling that such groups would not meet their individual needs.

When asked about specific problems with attending management and decision-making meetings, the majority of residents were most put off by the use of jargon, the time commitment and problems of finding and paying for child-care.

> ***"I didn't know these groups existed. No-one ever told me about***

> ***"They have meetings in the evening and I can't commit to it."***

> ***"I'm one of those people who don't like crowds. I get jittery meeting new people."***

> ***"They see them {those that get involved} as an elitist group."***

> ***"I already have strong support from my family and haven't had much to do with health visitors and midwives, so I'm not interested in giving my views."***

From NDC and Partner Organisations:
The agency staff identified lack of confidence, previous bad experiences and suspicion of those trying to better themselves as barriers facing residents who wished to get involved. They also identified some institutional barriers to people's involvement such as the need for a certain amount of bureaucracy so that resources can be accounted for. One interviewee expressed concern that central government procedures also undermined NDC's ability to support residents to become fully involved.

> ***People don't participate because: "They had bad experiences and they weren't taught a lot, except perhaps how to feel bad about yourself."***

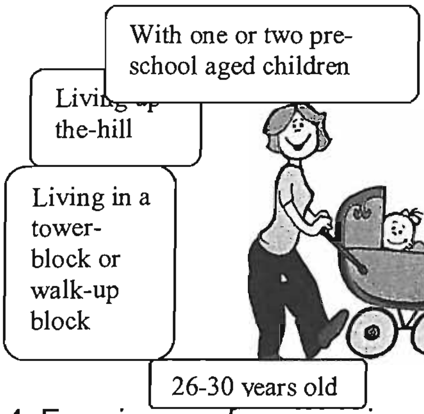
> ***"Right from the top you have this barrier stopping people getting involved."***

3. Who is more likely to participate?

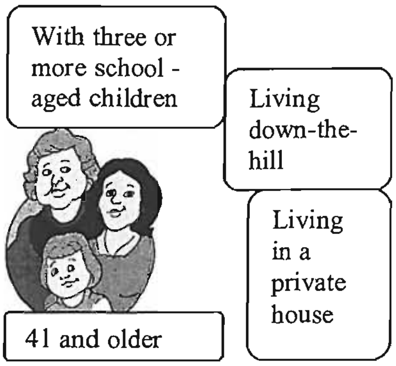
We interviewed 15 residents using a questionnaire, while this is only a very small sample there were some interesting results. For example, people living in the tower-blocks up-the-hill felt that [redacted] had a strong community whereas those living down-the-hill in walk-up blocks, particularly those of the 26-30 year old age group with pre-school children, felt that there was very little sense of community.

We asked the residents whether they were or had ever been involved in a community group or organisation – the diagram below illustrates the results:

Characteristics of those **least likely** to be involved in a community group



Characteristics of those **most likely** to be involved in a community group



4. Experiences of encouraging participation

There was much agreement from NDC and their partner agencies that trying to increase and sustain participation was a difficult task. However, many felt that there were several strategies that are more likely to work include

- using of a range of different approaches,
- asking residents already involved to encourage others,
- agency staff giving feedback and starting discussion on why changes suggested by residents can or can not be implemented and
- keeping events non-threatening and open to all.

Tailor made: ***"we are trying to tailor how people become involved in a broad way that can change people's lifestyles. There are times when people can commit a lot of time and there times when they're doing their own thing."***

Feedback and dialogue: ***"People had lots of issues and we turned up with the relevant council officers… we would come back with a response that we had thought about it and it doesn't work for a, b, or c and they came back again with another constructive idea."***

Informal: ***"We've done a picnic in the park, with lots of painting and water, where the parents sit around watching their kids, but then you can go and talk to them. They like things where they can just drop in, where there is not commitment and it's un-threatening."***

Word of mouth: ***"If they can recruit someone else by word of mouth, saying this is good, this is worth doing I think that is where the breakfast club has been quite popular."***

Conclusions

While the study was small scale it does raise some interesting points. Different groups of people in [redacted] face very different constraints to participating. It would seem that young mums with pre-school age children who live in the tower-blocks and walk-up blocks are particularly isolated and find it hard to get involved in either activities or decision-making structures. This is reflected in the greater number of older people with school-age children living in private houses who are more likely to be involved in decision-making bodies.

Staff in NDC and partner agencies were aware of the need for a whole range of approaches to address the different needs and constraints facing different groups of residents. However, often the residents identified issues such as the use of jargon, lack of information, the timing and style of meetings as constraints to their participation while the staff focused on issues of low self-confidence as blocks to involvement. Some of the issues raised by residents may be more straightforward to rectify within [redacted] Programme and NDC structures.

Appendix 6: Example of Part of the Analysis Chart

What (Theme)	Interpretation	Implications	Quotation
Empathy and lack of with residents (Differences between resident LFWs and non-resident HV and programme coordinator (ex-resident)	The LFW is relating directly to the experience of her friend and recognising this is similar to many mums in [redacted]. The HV has moved some way from this and aligns herself with the service 'our point of view' to such an extent that she is not putting the client's need before the needs of the professionals.	Illustrates the value of using LFWs from the community or similar. But maybe it is just a matter of time before they too put the professionals and their concerns over and above those of the client. Here the HV has been in the community for many years, but the LFW has only been working for 6 months	CR but it is difficult, I've got a friend who lives in Bournemouth a single mum who lives at the top of a walk up block and finds that she is very isolated et etc and she had a HV round to try and help her with her sons sleep problems and she really did not get on with the health visitor, she had a personality clash. I said well phone the office, speak to the manager and ask for a different one and explain that you have a personality clash. But it is difficult. ME: its difficult for both sides. CR: she didn't know, she's very intelligent but she felt that she was being given a gift of a HV and she should just accept what she is given. CR: I suppose from our point of view – I guess I don't get a choice of who I should visit. I mean you say that your friend should get a choice, but then I could equally say, well I should have a choice in who I visit, I might not like her. So it works both ways, its hard to please everyone in life. ME: although you could say, well you are paid and they are not! CR: for her she was saying that she wont see a health visitor again, and so now she is going to have this problem ad-infinitum which is no good for her. (AR Session 6)
	Lack of comprehension for people who don't get involved. The LFW talks about her own experience, and seems to find it hard to understand parents who don't go out and get involved. Maybe linked to her own sense of pride that she didn't do this but made the effort to go out. The other CR takes this further and strictly	The LFWs view could actually encourage other mums to get involved by drawing on her own experiences. But the HV view is intransigent. Again the benefits of having workers with direct experience of living in the/or similar community.	CR: like with my kids we went out and did something every single day, I couldn't stand being just in the house with them, gets so boring. CR: Basically you've got some who will do things and others who will just never get involved just take take take. Me: But there are some people that with a bit of encouragement they could get involved. (AR Session 7)

	categorises parents implying that they are either givers or takers		
	More realism than lack of empathy. There is a recognition that even working the system should be 'respected'.	The CR has worked as long as the CR, so is realistic about the way people behave, but she still maintains some empathy with the clients. Possibly because she has lived in [redacted] and brought her kids up here.	CR you are working with vulnerable families but also families who know to work the system and they know exactly what to do to get what they want, and I don't mean that disrespectfully. (AR Session 7)
	LFWs relate to how others will feel in group situations	Very valuable in deciding how to develop the service	CR: you have to be careful don t you of having one that overpowers the group, its group dynamics isn't it. so it might be interested to give them some training so they don't feel threatened in a group. Yeah I've been there, you are always sitting there thinking well should I say something? (Session 11)
	Seeing residents as screwed up		CR: what about this comment about 'if she had children herself' I mean we've all got kids CR: I think her expectation was that your children would be as screwed up as hers… maybe ME: there are quite a few saying they want more time CR: I think its difficult if you see them when the children are there and its hard to have a conversation. CR: yes, this one 'for the lfw to be in the same predicament'. I mean I don't think we want that. CR: yes imagine how they could have passed the employment procedure if they were as screwed up as some of them. (Session 5)
	Practical advice		CR: that is too much for residents.. I'm not being rude but if that came through my door and I wasn't involved I would bin it. CR: yeah we need to get it down to one piece of paper double sided. CR: I'm not being rude or anything but I know my kids, if you get something through the door, you just go flip flip flip and that's it isn't it? especially when you've got a kid tugging at your heals. So its got be brief. (AR Session 14)
	Personal experience of the clients problems		CR: a lot of things are so common that you are bound to have gone through it CR: and that's something that we can get across, that the problems these families are facing are really common. And a lot of them do feel

			isolated. CR: yeah everyone always thinks that everyone else is coping CR: but yeah its good for us to say, this is a common problem, this is what I found CR: I said to them we are all like swans, sailing serenely but paddling like hell underneath! (AR Session 5)
	Seeing residents as apathetic rather than keeping in mind why		CR: but there are also the people who don't do it because they've got nothing else to do, they just cant be bothered. Its fair enough if you've got something to replace it, but for lots of people round here they just cant be bothered. (AR Session 7)
	Result of lack of empathy leads to demoralisation,	Just thinking that clients are liars rather than why they might say that	CR: some families do just downright lie – they say they have never seen a health visitor and you pull out the notes and its there, visit, visit, visit (AR Session 8)
	Understanding what its like through personal experience	Having experienced a journey of participation	Cr: and getting those in the first week, cos that's when they start disappearing and don't come back. So you need something sound then and have a good atmosphere, if they are all sat round and they don't want to talk .. I've been there its horrible. AR Session 11
	Understanding what its like through personal experience		Cr: well I would have different questions because you've already done those. But did you feel comfortable – I mean no offence, but when my health visitor used to come round I used to hide behind the chairs!
	Being realistic through experience		CR: that is too much for residents.. I'm not being rude but if that came through my door and I wasn't involved I would bin it. CR: yeah we need to get it down to one piece of paper double sided.
	Lived experience of bringing up children in the area		Johny his breakfast before. If we had babies ,… attempting to be organised.. he had an early morning feed and then in the pram and then take the other two out to school and by the time you got home the baby wanted another feed.
Positive or hopeless about change	Hopeless about the community, exasperated at what would get people interested and involved	not triggered by the organisation, but has impact on morale. Linked to feeling that everything has been tried already. Slight glimmer of hope that NDC brings new funding.	CR: "I'd love to know what the community's issues are that they would come to. To be honest thats how I'm beginning to feel. So what is it that they would come to. AR Session 6 CR: it's about communication in a place with unmotivated people. I think that is hard for agencies as it is demoralising to work constantly with people who don't want to work with you. For me as a health visitor it is a jolly site easier working in hedge end where people are in for appointments, ring you and all that sort of thing. Whereas here you are slogging away with people who really don't want you there. Its not fair." (Ar Session 6) CR: "I think to be honest that we have all almost run out of ideas. I even struggle to think of things we haven't done and to know what type of areas they

			have done elsewhere. We can read it all in glossy magazines but when you really look into it, they haven't done the half of what they say they have done." (AR Session 6)
	Seeing slight changes	Having a positive attitude and building on small successes, potentially ideas then evolve into something that actually works.	CR I pre-empted her for the drop-in sessions, because she asked me and I said I know what you are going to say – 'I told you so', however, I've had two phone calls from people who apologised and said they wanted to come. ME: its like the more you do it…. CR Yeah its not a reason not to do it again. Id go back and do it again. (CR Interview)
Lack of influence of frontline workers over their service	Recognition of challenges in making decisions. Inferring that it used to be different?		CR: the trouble is I think society has become, so that people who are relatively on the ground are not allowed to make decisions, because of all the political correctness, they are not allowed to do it anymore, so we are almost making decisions in a straight jacket, because the people that we need to make the decisions are running from one meeting to another and are completely inaccessible. (AR Session 7)
	Working through a bureaucratic system as has no direct influence on decision making.	Ideas take much longer to be implemented or maybe don't happen at all. Those lower down have to find ways round the problem	CR: I'm still waiting for someone to come back to me on that. I did mention it last week when we went to see Clare.. she's given it to Barbara - who has to put her eyes over it apparently. I haven't put any logos on it purposefully. I explained in the email to do it as a one-year pilot and then see if the PCT wanted to own it and then develop their own system. (AR Session 8) CR: Liz has looked at it as my line-manager, she said I have to show it to Clare, who then passed it on to Barbara! So I'm waiting for her to come round. (AR Session 8)
	Lack of budget to support participation	Slows things down, frustrating, disempowering for all. Leads to sense of hopelessness	ME: yes we'll have to think carefully about how they work. We should definitely provide child-care. CR: but how do I pay for it Helen? ME: but last time we spoke.. didn't you… huh…didn't you say you could maybe get £50 or so to pay for it? CR: maybe as a one-off, but not on a regular basis. (AR session 9)
	Can't make the changes needed	Feeling unable to change small things within the service (because of lack of influence/budget) argument against feedback/participation	CR5:. When I've done questionnaires before, and we used to have one for Parent Craft, people would always complain about the uncomfortable green chairs, over which I had no control. But if its something that you can t change then what happens? (Ar Session 5)
Seeing the bigger picture	Starting to see how participation links in to outcomes and overall programme goals	AR seems beneficial in helping members to start thinking of the wider service and what they are trying to achieve.	Cr: so its back to that thing of what you measure! ME: yes, but its also what they see as important, so maybe health and education improvement are the most important thing and working towards community ownership is not. So maybe the focus is wrong – not wrong, but community ownership doesn't figure in the outcomes CR: yeah – it doesn't come into any of our outcomes,

			Me: so maybe all they are interested in is..... CR..... whether they've given up smoking. Ooooh its giving me a headache.! (AR 6)
Not seeing the bigger picture	In the AR group discussions the focus was often on individual clients and their relationships with them,.	Found it hard to think of the wider service and developing systems within the service to respond to common situations	ME; is there something you can do about those comments to make sure advice is consistent? CR: its about how people hear information Helen, I mean you could say the same thing to someone and they would report back and say you had said two different things. ME: but is it something you need to check that you have got a system that stops inconsistency. (AR Session 13) "CR: there was no way she was going to get what she wanted as she didn't meet the criteria for that service. ME: did she understand that though? CR: well obviously not. ME: so that's the point about being clear about exactly what the family workers can and cant do. I know its hard when you know exactly who it is, but its whether you can pick out general lessons that could then shape what you do." (AR Session 13)

Appendix 7: Education Action Research Paper: Action Research and Organisational Change

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Using Action Research to Stimulate Organisational Change within Health Services: Experiences from two Community-Based Studies

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Abstract

The relevance of action research to organisational change within contemporary health services in the UK is discussed in this paper. Two examples of collaborative community-based studies are presented; one exploring ways to encourage community participation within a health and regeneration programme and the other considering the types of knowledge used within a 'community of practice' to develop services for older people. The studies highlight the value of action research in bringing together citizens and health professionals to reflect on practice and to explore ways of improving service delivery. The paper concludes that such 'time-out' is important in supporting staff to internalise and shape processes of change. Furthermore, the forum which action research provides to bring staff and citizens together to plan, reflect on and evaluate their actions helps not only to develop services but also to challenge some of the traditional organisational processes which have excluded users and citizens.

Key words: action research, organisational change, user participation, communities of practice.

Introduction

The link between action-research and organisational change stems from Lewin's (1947) ground-breaking work with US corporations. Lewin's action-research emphasised the importance of group work and the participation of those affected in ensuring an effective process of change. His work led to understandings of group dynamics and the processes through which participants have to go through in order to achieve change. He named this process unfreezing, moving and refreezing. More recently, French and Bell (1990) point to a 'strong family resemblance' between action research and organisational development.

The NHS has been characterised as a complex organisation in a continual state of change (Smith et al. 2001; Cortvriend 2004), during which frontline workers often feel bombarded and overloaded by new structures and ways of working. As such, employees experience "a constant cycle of change with little time for stabilisation or adjustment, leading to negativity and lowered motivation." (Cortvriend 2004:177). Given this climate of continual change within such a complex environment, Wye and McClenahan's (2000) research, which looked at how best to ensure evidence based practice within the NHS, concluded that change within the NHS can never be straightforward and linear. Furthermore, to be successful the proposed change process has to be interactive, to offer benefits of interest to front-line staff and to relate research to current practice. Hence it would seem that action-research, particularly within the participatory mode, provides an ideal approach as it attempts to bring research and theory into practice whilst also being interactive. This paper presents the experiences of two action-research projects which are aimed at creating organisational change in health. The first relates to a community health programme within a regeneration area, with the objective of stimulating community participation in the activities and the management of the programme. The second is focused on the development of health care services for older people, through the establishment of 'communities of practice' and the use of different knowledge sources, it involved citizens working alongside health and social care professionals and practitioners.

Developing an organisation

There have been several attempts at synthesising the literature on organisational development (e.g. Ackerman 1997; Armenakis and Bedian 1999; Iles and Sutherland 2001), resulting in a common observation - that organisational change is not fixed or linear and invariably contains an important element of emergent and unplanned activity. Armenakis and Bedian (1999), in a review of research during the 1990s, concluded that the success or failure of change processes is dependent not only on the external context within which the organisation operates and the content of the organisational changes, but also on the *processes* used to implement the change.

Kotter (1995) has identified 8 steps for effective change (see Box 1).

Box 1: Steps in the process of change

1. establishing a sense of urgency by relating external crises/opportunities
2. forming a powerful coalition of individuals who embrace the idea
3. creating a vision
4. communicating the vision
5. empowering others to act
6. creating short term wins and publicising success
7. consolidating improvements and changing other structures, systems etc.
8. institutionalising the new approaches by publicising change and success

Kotter (1995)

Kotter's (1995) elucidation helps to flesh-out some of the practical steps in relation to the concepts identified by Lewin (1947). Lewin's concept of unfreezing, which involves recognising the need for change and looking for root causes of problems may well be stimulated by the first couple of steps. Creating and communicating a vision, empowering others and short term wins could help with the 'moving' phase - where information helps to generate new beliefs and values. Consolidating improvements and institutionalising are closely linked to refreezing – where new values and beliefs are internalised (Bullman, 2003). It also concords with Armenakis and Bedian (1999) who suggested that "the change process typically occurs in multiple steps that take a considerable amount of time to unfold and efforts to by-pass steps seldom yield a satisfactory result." (p. 303)

Resistance to change and support for staff through the process are other themes within the literature. Jaffe et al. (1994) and Isabella (1990) identified possible stages for employees in the change process. First, there is denial as employees refuse to believe that change is necessary or will be implemented and this may involve initial resistance to act. This is followed by an exploratory phase when people start to try out new behaviours, and finally, there is commitment to the new situation. This process needs time to achieve and Cortvriend (2004), following a study of a Primary Care Trust merger, questions whether this is realistic, because the need for immediate change leaves little time for stabilisation or adjustment

Spurgeon (1999) asserted that within the NHS, "organisational development has tended to become a largely reactive process attempting to implement, accommodate and at times ameliorate the impact of a range of externally driven policy initiatives." Hence, "initiatives aimed at shaping organisations can often be perceived as gimmicky and transient, thus creating a negative and cynical audience" (Spurgeon 1999:25). To improve the effectiveness of change processes, Spurgeon (1999) recommends reducing distance between managers in the hierarchy and importantly, meaningful delegation to and empowerment of staff, improving 'shared meaning' among all levels of staff and providing supportive and secure environments where staff can try out new approaches and learn new skills.

Action research and organisational development in health

The literature relating to change in the health services clearly indicates that there is a need for greater participation of staff at all levels of the organisation, and the development of shared understandings about the purpose of change. In addition, it is important to allow a relatively safe environment for people to try out new approaches, combined with sufficient time for individuals to overcome their inherent resistance to change and fully adopt the new mode of working. Alongside this is the increasing emphasis on the appropriate involvement of service users and potential recipients of health services in the development of services. Collaborative action research provides the ideal forum for bringing together different levels of staff with service users and citizens. Therefore it is unsurprising that action-research has been an approach favoured by those engaged in health services organisational development – both providers and users.

While the spectrum of action research approaches is wide (Hart and Bond, 1995) the more recent attempts at organisational development which focus on the need for participation of staff and service users are based on the use of action research as a tool for empowerment. Here the concepts of participation are key, with great emphasis placed on the equal involvement of all within a group of co-researchers with the aim of stimulating such empowerment (Reason and Bradbury 2001). While such concepts are key to the theory of participatory action research, expecting such equal relationships to exist in practice is argued to be unrealistic as McTaggart notes.

"Participatory action research is in principle a group activity. But in situations where people with different power, status, influence and facility with language come together to work on a thematic concern, the idea of participation becomes problematic." (McTaggart, 1997 p.28)

Working as a group of co-researchers provides a forum of reflection, which may well help the change process not only in improving its relevance to the wider context, but also in providing participants with a space to create joint meanings and understandings of the changes they are attempting to make. There is also the opportunity to gather immediate, locally relevant information which can be combined with evidence from further afield and with relevant theoretical perspectives.

Action research has been used to facilitate change in health services both internationally and in the UK. For example, Shani and Eberhardt (1987) established collaborative groups or 'parallel organisations' of employees within a US health provider; the parallel organisations used cycles of data collection, reflection and action in order to implement significant changes to team working within the organisation. In Australia, Tobin et al, (1997) were able to encourage change in mental health services by collecting data and presenting it back to mental health practitioners for discussion and reflection on a cyclical basis. Kennedy (2001) used action research in Liverpool to help health professionals reflect on their health promotion practice. This resulted in a change in attitudes towards lay people's knowledge and initiated the recruitment of community members as nutrition outreach workers in recognition of their superior understanding of the causes of poor diet among their community.

Two examples of the use of action research to create organisational change in health care are now presented in more detail. The first is an ongoing project, for which Helen Elsey has been the key researcher and the second is a completed project by a team of researchers, led by Judith Lathlean. These studies will be critiqued in terms of the lessons learnt for effective organisational development and the part that action research can play in this process.

Project 1 – Encouraging Community Participation

Background

The study is based within the health programme of a 'New Deal for Communities' (NDC) regeneration scheme. The NDC scheme has been allocated just under £50 million of central government funding for a period of 10 years in order to improve the education, employment, environment, crime levels and health of the approximately 11,000 residents. The health programme in which this study is based provides support to families in the area with children from 0-17 years old and is built on an NDC-led partnership between the primary care trust, the hospital trust, social services and several voluntary groups. One of the core aims of the NDC scheme is to increase community involvement and ownership of the regeneration activities. Hence this action-research study aims to increase resident participation in the activities and decision making of the programme.

Whilst working towards this aim, the study has highlighted the opportunities and constraints facing organisations keen to develop a more participatory mode of working. The staff involved in the programme were eager to move from a traditional approach where health professionals are assumed to 'know what's best' and clients merely take what is offered, to a more community development approach where participation is seen not only as a right (International Covenant on Civil and Political Rights, Article 25), but also as a means of increasing the appropriateness and effectiveness of the programme (Narayan, 1995; Crawford et al. 2002) and helping to empower the client (Schulz et al 1995; Cattell 2001).

Action research was chosen as the most appropriate approach for the study due to its key characteristic of collaboration among participants or co-researchers and the flexibility the action-research cycles provide to systematically try and evaluate new approaches. When attempting to become a more participatory organisation, flexibility is vital – there are no blue-prints for achieving community participation; approaches and techniques need to be applied and adapted to the requirements of the local community. In addition, the participatory, collaborative approach was of fundamental importance if the study was to 'practice what it preached' – that participation is beneficial and should be encouraged.

The design of the action research

At the heart of the study is a core group of seven co-researchers, all of whom volunteered to join the study. These include three community health workers, a health visitor, a resident, the programme co-ordinator and the facilitator/researcher (Helen Elsey). On the spectrum of action research identified by Hart and Bond (1995), the study falls between the empowering and the professionalizing type. According to Hart and Bond's (1995) criteria the study shares characteristics of the professionalizing type in that it has been led and predefined by professionals and the facilitator/researcher. The study aims to "identify causal processes" within the intervention, which Hart and Bond place under the professionalizing type but also to "change the course of events" which fits better under the empowering type (Hart and Bond 1995 p.43). Furthermore, the study was intended to raise the consciousness of all its co-researchers, enhance user control and shift the balance of power – all characteristics of the empowering type – rather than merely "enhancing professional control" – a characteristic of the professionalizing type (Hart and Bond 1995 p.40). These distinctions are helpful in understanding the nature of the study, particularly when considering issues of power and possibilities for equal participation within the group (McTaggart 1997).

The group has met roughly every four weeks over a year. Initially, a reconnaissance phase was conducted where members of the group conducted interviews, questionnaires and group exercises with residents, health and regeneration staff and other stakeholders to explore what helped and hindered participation. The findings of this first phase provided the group with the information needed to try out different strategies for encouraging participation within the action research cycles of planning, acting, observing and reflecting. A final evaluation of these strategies will be held in July 2005.

Strategies to encourage participation

Throughout the study, the facilitator/researcher recorded and transcribed all action-research sessions and individual interviews with the co-researchers, and facilitated joint analysis of the reconnaissance phase data. While the project is ongoing, from an initial analysis (using a 'framework approach', Ritchie and Spencer 1994) strategies have been identified as encouraging participation. These are:

4. improving information about services and how community members can get involved through leafleting, articles in newsletters, word of mouth and worker support.
5. setting up feedback systems where service users can give compliments, complaints or suggestions on how to improve services and the service providers respond to their feedback. This included feedback forms, community meetings and drop-in session and a service for views to be sent by text to a partner organisation.
6. strengthening resident involvement in the decision-making structures within the programme. Particularly in establishing a parent's panel to design services and activities.

On the surface these strategies may appear to be fairly straightforward to implement; however in practice it became clear that to institutionalise these changes requires both a cognitive and a practical shift away from traditional ways of working within the health services involved in the programme. Hence, facilitating the group to think through the meanings of participation and why they might want to encourage feedback and participation in their services became a key focus for the action research group.

How action research helped to encourage organisational change

During the early sessions of the action research group there was much debate and discussion about what participation meant for the programme. Drawing on theories and interpretations of participation from the literature was helpful in encouraging debate and reflection. The process helped in developing shared meanings about participation and also clarifying the goal to which we were working. The data collection in the initial reconnaissance phase helped to build an understanding of residents' experiences of trying to participate and also of the views and experiences of statutory agencies and voluntary organisations in trying to stimulate participation.

There is a danger with action research that the initial reconnaissance phase, with its many interviews and questionnaires, usually led by the key facilitator/researcher, is seen by the co-researchers to be too long-winded and academic. However, this phase proved to be interesting and motivating to the co-researchers, particularly those that were able to play some part in data collection. For the more junior co-researchers conducting interviews seemed to boost their confidence to raise and debate issues within the action-research group. As one said:

"I really enjoyed doing [the interviews]- it was really good fun. And it sort of opened my eyes to how many people just don't know what is going on and their feelings about joining groups and their own lives."

In terms of organisational development, this phase of data collection, the theoretical input and reflection went some way to address the unfreezing process and the first three steps as identified by Kotter (1995), i.e. developing awareness of the constraints to participation facing residents in order to create a sense of urgency, build a strong group with a shared purpose and create of a vision.

While this phase was clearly beneficial in developing shared meanings and ideas about participation, it should be noted that, through the action research cycles that followed, these were continually challenged by the realities of attempting to implement them in practice. This helped the group to explore the boundaries of participation, particularly given the complex institutional environment in which they were operating, with many different health and regeneration partner organisations.

Another positive contribution of action research to organisational change is the opportunity it provides for challenging the processes organisations use as well as the way they deliver services. The action research group formed in this study not only brought together staff of different levels within the programme, but also included a resident member. This helped to demonstrate first hand to the co-researchers the value of having citizen participation within the planning and evaluating aspects of the organisations work. As one of the staff co-researchers explains:

"She [the resident member] gives a fresher view point really. She tends to bring a view point from the ground level – if you like. All us airy-fairy theoretical bods say something and she goes, 'no it wouldn't work...it's not like that!'"

The ongoing cyclical structure of the action research project brought further benefits in terms of maintaining focus on the desired organisational change, i.e. improved community participation. Keeping this focus is particularly challenging in the complex working environment experienced by this kind of health and regeneration programme with its many different partners and their intertwining bureaucracies. The regular meetings and cyclical process of action research helped to give a structure and continual drive to the process. This in turn helped to ensure that the strategies identified by the group remained on an already overloaded agenda and, as the programme coordinator explained:

"From my point of view I've found it [being part of the action research group] really quite useful because it has steered some of the things I've decided to do, because it has been an opportunity to think about it and think about how we actually take something forward."

As the group discovered in the reconnaissance phase, the community faced many constraints in their attempts to participate at any level within the programmes in the regeneration area; particularly the lack of childcare provision and inconvenient meeting times, the lack of information about opportunities to participate, the jargon and inaccessible language used by agencies and feelings of anxiety about joining groups and meeting new people. It is inevitable therefore that the strategies being tried by the group met with many challenges and were often only of limited success in the short-term. However, the space provided by the action research group to clarify the blocks to participation and think through alternative ways to address them, most importantly by developing a system for listening, hearing and responding to resident views was valuable. Moreover, the session provided the motivation and encouragement to keep the process alive. The action-research cycles gave the co-researchers the chance to experiment and try out new approaches within a supportive environment.

Challenges in using action research to encourage organisational change

Whist the group has made good progress in instigating changes, actually moving through all the steps identified by Kotter (1995) has been very challenging. Given the one-year time frame of the action research and the extent of change required in both organisational systems and culture, this is to be expected. Specific problems can be identified. For example, the composition of the action research group is vital. In this study, none of the co-researchers were decision-makers with control over a budget to support the strategies identified by the group. This was exacerbated by the traditional role of those at the lower tiers in the NHS who have rarely been required to look beyond the needs of individual clients to think about the wider service issues. The programme co-ordinator, who was a member of the group, had line management of programme staff and was accountable for the outcomes of the programme, but did not have direct access to a budget to support the strategies identified by the group.

This has clearly been a learning point for the programme, which the second phase of funding for the programme is seeking to address. Nevertheless, this does raise some interesting tensions in terms of using action research as an approach for organisation change. One solution could have been to target budget-holders during the recruitment of co-researchers, but encouraging equal participation of all those in the group is key to this approach. Even with the mix of different management levels in the group, facilitation to stimulate the participation of lower-level employees was challenging. As one of the co-researcher explained:

"[The line managers] can be a bit intimidating, not in a nasty sense, but just that they've got such a good grasp. Especially [one particular line manager], she's got so much experience; I don't think I can compete with that. So sometimes it's easier not to say too much."

Kotter (1995) identified the value of 'quick wins' in terms of encouraging the wider organisation to begin to take on board the organisational change. The time available within most action research studies for reflection and group discussion can mean that quick wins are hard to come by, and this was equally true for this study. In addition, the more experienced members of the group had to work hard to overcome feelings that all the strategies had been tried before with limited success. As identified above, the value of action research in this setting was that it provided space for staff to think through and respond to a key aspect of their programme – community participation. This may well have gone some way in helping them to move through the processes of change on an individual level and some specific programme changes, but broadening this out to the wider organisation in such a short time-frame was beyond the reach of the study. However, the members of the action research group are keen to continue advocating these approaches to their colleagues and the project has provided the ideas and empirical evidence to help them do this.

Project 2 – Developing services for older people through communities of practice

Background

The origins of this project, which was funded by the NHS Executive South East Region Research and Development Directorate, lay in two agendas prominent in the health and social care arena - user/lay involvement in service development and knowledge management. The project was aimed at the development of services for older people within the areas of two Primary Care Groups (PCGs), building upon existing local work which had been undertaken as part of the Better Government for Older People (BGOP) initiative (Cabinet Office, 1998). The idea was to explore how knowledge was managed by those involved in service development through the creation and evaluation of two "communities of practice - CoPs" (Wenger, 1998). (The definition used for the project was that of Wenger et al. (2002:4/5) which describes communities of practice as "groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis".)

As such there was a need to blend research and development within one study and for this a multi-disciplinary, multi-professional research team was instigated involving a project lead (Judith Lathlean), two project team members who were also the facilitators, a further two members who were primarily advisors, and two researchers/evaluators who collected and analysed the data.

Design of the CoPs and their evaluation

The purpose of the two multi-stakeholder CoPs - one in each of two Primary Care Groups (PCGs) - was to bring together consumers (in the broadest sense), designers, providers and evaluators of health and social care services. The topics of their work were identified by consumers (referred to as 'citizens') through focus groups prior to the establishment of the CoPs and they centred on improving local health services for older people; the first topic was intermediate care and the second was discharge planning from hospital into the community. The plan for the evaluation was to observe, analyse and evaluate the development, functioning and maintenance of the CoPs, focusing on the features that help and hinder their workings, and to contribute empirical evidence to the theoretical understanding of the processes of knowledge management taking place in the CoPs.

An action research design underpinned the project and it was chosen to describe, evaluate and offer a mechanism for the development of services since it is inherently practical, change-oriented, cyclical and participatory (le May and Lathlean 2001). One CoP involved 26 people in total, including health professionals (nurses, managers, a GP), lay members of the PCG and citizens taking part in the BGOP initiative, voluntary and independent sector representatives and social service managers. Whilst this may be considered a rather large number for any one CoP, the anticipated fluctuating attendance meant that the maximum attending on any one occasion was 15 and the minimum seven, and new members were invited as the need for their inclusion was identified. The other CoP involved 21 people, with a maximum of 10 attending on any one occasion and a minimum of 6. The type of members and the balance between the different groups was very similar for both CoPs. Each CoP met on 7 occasions over a period of 7 months.

Two members of the project team facilitated each CoP meeting, and a researcher/ evaluator undertook observation of these meetings, as well as interviewing CoP members on a number of occasions over time. It is important to recognise that the model of action research in operation differed from that in the previous example (Project 1), in that here there was no notion of co-researchers. Rather the project team was a separate entity but it worked closely with the Communities of Practice and their membership in order both to facilitate the processes of the CoPs and to understand and evaluate them as they proceeded.

The Communities of Practice in action: factors affecting their functioning

The choice of topic - which involved both consumer focus groups and the PCG Chief Executives - played a large part in determining the composition of the CoPs. This required considerable input from key actors involved in the delivery of the service, such as the Chief Executives and leads for Services for Older People, which may have biased the initial composition of the CoP. The choice of topic was also crucial to the commitment of the CoP members to the groups' task, and their motivation to do the necessary work.

Mix of membership was also important. On the positive side, meeting people from other organisations was valued. For example, one member suggested:

"I found it interesting working alongside people from the different agencies and people's viewpoints and I think it is quite comforting in a way that people were actually thinking along the same lines..."

However, although the involvement of lay people and a variety of professionals in the group was a deliberate feature of the design of the CoPs, the value of the contribution of members from different backgrounds needed repeated reinforcement by the facilitators. Eliciting the varied skills and expertise from all members was further complicated by the fact that some of the professionals in the group were already used to working together, whereas many were not.

Fluctuations in attendance tended to be problematic. The CoPs continually evolved their membership to handle the topic more effectively, which was both beneficial in bringing in new key skills and expertise, but also disruptive to the development of group cohesion and continuity. As one member said:

"You get a back track all the time ... and it seems unfortunate, as time is wasted explaining the same things to new members".

Inter and intra-agency relationships were critical features. The roles of CoP members in their parent organisations were vital to the functioning of the CoPs not only because those links with parent organisations formed an important two-way conduit from the CoP to the key decision-making bodies, but also because the power of the group to effect change depended to some extent on the capacity of its members to influence those organisations. This indeed was one of the main reasons why it was felt important to have people as members of the CoPs who were in position to take the work on further – such as PCG Chief Executives and service leads – or at least to have their considerable commitment to the CoPs.

Understanding the purpose of the CoP was key to its effectiveness. Because CoPs are a relatively new concept, much work needed to be done at the outset to clarify the nature and purpose of the group, and to manage expectations. The facilitators needed continually to revisit and clarify the goals of the group. Indeed the facilitation was very important to the functioning of the groups, and required a range of techniques to ensure that relevant knowledge was shared and captured, properly processed (as far as possible) and used in the service of the groups' tasks.

How action research helped to inform organisational change: successes and challenges

An action research design was employed in this project, using CoPs as the vehicle of choice, to develop services in health care. The proposition was that by facilitating these CoPs to acquire, adopt and use a range of sources of knowledge in decision-making, this in turn would inform organisational change i.e. a better approach to the development of intermediate care services or better discharge planning.

One of the major findings of the evaluation was that the CoPs did not follow the conventional and relatively linear tenets of the evidence-based model of practice, especially initially, despite considerable efforts (e.g. facilitation, agenda structuring, library services) to help them to do so. Rather, they exhibited the more socially determined and dynamic patterns of collective sensemaking and decision-taking that have been described in other contexts. Knowledge was unpredictably contingent on group processes. Despite the efforts of the facilitators to regularise knowledge management in the CoPs, much of the uptake and use of knowledge was relatively haphazard, and dependent on the experiences, interests, and skills of those members who happened to be present at a given meeting. Members tended to make do with whatever knowledge was to hand when a given decision was needed.

Nevertheless, over time the CoPs did tap into a wide range of knowledge sources including experiences and service-related stories, local documentation, local people and experts, information from the internet as well as journal articles and other publications traditionally associated with evidence-based policy making. The types of knowledge also included experiential, contextual, organisational and practical as well as empirical or theoretical knowledge. The groups tacitly and rapidly established a common currency for their discourse, which tended to rely on experiential and contextual knowledge, in particular stories and anecdotes. However, this may be a more powerful way of influencing organisational change because people can 'own' the knowledge and relate to it better.

The acquisition and uptake of new knowledge was shaped by personal, professional and political agendas rather than the principles of systematic searching and critical appraisal. The collective sensemaking of the CoPs was influenced by changing internal and external agendas, roles and power-relations, for example, lay members bowing to the perceived knowledge of certain professionals in terms of 'technical' matters. There was often a discernible relationship between the types and sources of knowledge used, the knowledge behaviours of the group members, and the roles and agendas that the group members had within the CoPs and in their own day-to-day roles. For example, professionals and lay members alike were adept at bringing forward stories and anecdotes to support their own positions in a discussion.

Clearly it would be dangerous to conclude too much from these two CoPs, not least because they were deliberately established rather than naturally occurring situations. These were not existing managerial groups with line management responsibilities, but specifically constructed groups, intended to develop policy advice while helping the health service to further understand the processes of knowledge management in multi-sectoral groups. Nevertheless their composition resembled that of many groups now engaged in policy making in the health and social services and therefore the results may be transferable to other groups engaged in such work.

The intensive facilitation was also a particular feature of these CoPs, which is unlikely to be replicated in naturally occurring decision-making bodies. The facilitators - deliberately treading a careful line between enabling the groups to proceed "naturally" and pressing them towards following the traditional methods associated with evidence-based practice - did as much as possible to ensure wide participation amid a diversity of interests. The results need to be interpreted in that light. It could be argued that the facilitators were too active in advocating the use of certain types of published, research based evidence when this seemed to go against the grain of the groups' preferred working patterns, and that the use of research based knowledge may therefore have been more prominent in the latter meetings of the CoPs than it might naturally have been.

In terms of how successful these CoPs were in effecting or at least influencing organisational development and change, whilst the action research confirmed the importance of collective sensemaking, and emphasised the socially constructed nature of knowledge management within the communities of practice, the impact they had on local policies for intermediate care and discharge is debatable. Although active as multi-sectoral debating forums, the CoPs ceased to exist beyond the seven meetings, and any further action was the result of lobbying by individuals. (For a further discussion of this project, see Gabbay et al. 2003.)

Conclusions

While these two projects were different in design and content, there are some clear similarities in the lessons that can be learned from their implementation in practice.
Both studies have highlighted how the composition and structure of the 'action' group can influence the direction the group takes and its effectiveness in making progress towards organisational change. Having members or co-researchers with decision-making authority and access to budgets within the action-group is important if the group is to have a wider impact on services. In situations where decision-makers are not involved in the group, a clear constitution that involves different layers and levels of strategic planning as well as effective links with decision-makers outside the group can be of great benefit in promoting the group's wider influence.

Another lesson learned is the value of recognising and making use of different types of knowledge. Both projects drew on research evidence, experiential, contextual and practical knowledge to explore their respective topics of interest. This use of knowledge, coupled with reflection, debate and discussion helped to stimulate understanding and critical thinking among group members, which in turn helped to increase the recognition for the need to change and to identify problem causes. This may well serve to 'unfreeze' organisations stuck in traditional ways of working.

The inclusion of lay or resident members was a fundamental principle of both studies. Their active involvement was beneficial in challenging professional view points and offering alternative perspectives on the experiences of users and citizens. This aspect of participatory action research has the advantage of adding a wide range of perspectives to assist in the improvement of services and importantly, helps to demonstrate the value of citizen involvement first-hand to the staff members of the group. This can potentially change not only *what* services are delivered, but also *how* those services are delivered by, for example, increasing lay involvement in the processes through which services are designed, delivered and evaluated.

The experiences of both projects in facilitating diverse groups through a process of change also offer some useful lessons. Firstly the style of facilitation is important, particularly when the group consists of lay members and staff from different managerial levels. Recognising that the equal participation advocated within the action research literature is often an ideal allows the facilitator to identify and address differing power dynamics within the group. As well as using participatory facilitation techniques during the group sessions, both studies actively explored ways of empowering group members who felt uncomfortable expressing their views in front of more senior managers or people seen as inherently being more knowledgeable. One strategy that proved particularly effective was involving co-researchers or group members in collecting data through interviews or surveys. This helped to develop their confidence with the issues being explored and also gave weight to their views when aired in the group. Both studies aimed to go beyond data collection, reflection and discussion to actually stimulating organisational change. A strategy that proved effective here was inviting others to join the group, for example in Project 2, a key Health Authority representative (a Consultant in Public Health) was co-opted to facilitate the group in constructing their business case, based on their initial work, once the project had finished.

Clear lessons have been learned from both these projects on the how to use action research to stimulate organisational change. Careful consideration of how to involve key decision-makers within the group either directly or through communication mechanisms is needed. The inclusion of lay members within both the projects proved valuable in not only bringing in different types of knowledge to the group, but also in changing organisational perceptions of the role of citizens within the processes for designing and delivering services. Recognising power imbalances within the group and identifying strategies to support the empowerment of lay and more junior staff members are key to encouraging more equal participation within the group. Finally developing facilitation strategies to help the group move beyond discussing the available knowledge to developing policy or action plans is vital if the wider organisation is to begin to move through Lewin's (1947) stages of unfreezing, moving and refreezing.

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