COMMUNITY PARTICIPATION IN HEALTH INITIATIVES: A GUIDE FOR PRACTITIONERS

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Abstract
This literature review aims to synthesise existing theories of community participation in health programme planning, the importance of community participation in these planning activities and how they affect programme success, as well as exploring the common barriers to robust community participation. In so doing, the authors hope to provide a succinct yet comprehensive guide to public health practitioners interested in effectively incorporating community participation into health initiatives. Of particular importance, when considering community participation in programme planning, is the lack of homogeneity within the community that might contribute to established power differentials and various barriers that may prevent equal participation from all community members. Implementing a fluid approach to community participation design may be more effective in guiding community involvement, and eliciting genuine participation from community members, as opposed to the alternative of instituting concrete policies that could have a top-down flavour.

Introduction
Community participation was solidified as a definitive public health strategy at the conference of the World Health Organisation (WHO) and UNICEF in Alma Ata in 1978. WHO articulated that the focus on community participation underscored a need for collective action and empowerment within communities to achieve well-being and health (Zakus & Lysack, 1998). Since the Declaration of Alma Ata, however, much discourse and analysis have centered on the consolidation of a definition of community involvement in terms of: 1) level of involvement on the part of the community; 2) the groups represented in community participation, and 3) the procedures governing community participation (Botes & Rensburg, 2000; Boyce, 2001; Corbie-Smith, 2004; Higgins, 1999; Macfarlane, Racelis, & Muli-Musliime, 2000).

This paper will provide a general framework for community-based health initiatives by discussing how community involvement is initiated and controlled within communities, how various factions within a community can be incorporated and heard, and how community organising guidelines can be made specific to each community’s unique characteristics.

Levels of Community Participation
Community participation has been defined as the ability of communities to assume responsibility for determining their own health needs, to decide on effective and appropriate solutions, to develop organisations centered around these endeavours, and to monitor and evaluate continually the effectiveness of programmes, as well as to tailor any existing goals to emerging circumstance and need. Many scholars, however, recognise that community participation can take multiple forms, with some asserting that the terminology of community participation is often invoked but not truly understood (Botes & Rensburg, 2000). Governments or
agencies accepting it as desired by the community, thus leading to effective decision making and more empowerment may utilise involvement to co-opt community participation to expedite externally implemented policy (Boyce, 2001; Morgan, 2001; Church et al., 2002). The empowerment approach tends to focus on the process of delineating needs and resolutions in a bottom-up (originating from the community) fashion that aims to establish ownership of projects and social capital within the community. A more results-driven approach may use existing community structures to implement top-down (originating from external agencies) policy (Morgan, 2001).

Many conceptual levels of community involvement have also ensued. On one level, community representatives may be allowed to attend policy meetings, but are not permitted any input into policy decisions (Church et al., 2002). On another level, agencies and organisations may become more responsive to disadvantaged individuals within a community, even documenting the need for attention to marginalised populations in mandates such as in the Health Promotion Contribution Program (HPCP) in Canada (Boyce, 2001). Many discussions have centered on the use of community participation in increasing the sustainability and longevity of health programmes. Utilising the terminology of community participation may also be a technique to lower levels of expenditure for agencies by cost-sharing with communities, for example when donors or governments use community resources (land, labour and money) to offset the costs of providing services, or that project costs can be borne by locals without further international aid (Morgan, 2001). There is the potential, however, for community members to become true partners in public health discussion.

Church et al. (2002) conceptualises the levels of community involvement as rungs on a ladder. The lowest rung is when officials or professionals alone decide policy and what information is going to be disseminated. The next rung consists of communities being asked to contribute their opinions, but without any guarantees of action. A higher rung envisions communities sharing responsibility in the decision-making process alongside officials or professionals. The very highest rung reflects communities in control of decisions.

A leading expert in community studies, Rifkin designates five levels of participation in health (Kapiriri, Norheim, & Heggenhougen, 2003) that give more detail about top-down product-driven approaches versus bottom-up process-oriented techniques. The first occurs when communities are viewed solely as beneficiaries of programmes, services and education that are externally derived by international agencies, organisations or governments. The next level discusses the use of local labor resources, existing social frameworks or finances in externally derived initiatives. A third level of involvement consists of local populations being enlisted for management positions in the carrying out of programme activities. One level up from this occurs when local populations actually monitor or evaluate projects. The highest level envisions communities deciding exactly which programs are to be implemented and what they would expect from external sources in terms of knowledge or resources.

Despite the Declaration of Alma Ata's endorsement of involving communities in decision-making processes relating to health needs, many top-down agendas were implemented in the 1980s and 1990s (Macfarlane et al., 2000). Botes & Rensburg (2000) argue that community participation does not occur if there is no consultation with the community, and that emphasis should be placed on facilitating solutions specified by the community rather than attempting to impose de-contextualised and pre-existing plans onto communities. Research from the 1980s displays an overarching control by international agencies, not only in defining health needs but also in implementing product-oriented programs that rely on generalised trends rather than actual needs as specified by communities (Morgan, 2001). The failure of many such top-down approaches inspired the need for a deeper level of community involvement (Korpela et al., 1998).

The World Bank has declared that community empowerment and self-actualised solutions are a better answer to the absolving of health disparities after conducting a study that found that there was more trust in local groups and a greater distrust in larger organisations, resulting from inappropriately implemented projects (Macfarlane et al., 2000). Authentic community-based initiatives by bottom-up organisations have been shown to have greater
potential to succeed where inappropriately applied top-down solutions have failed (Macfarlane et al., 2000).

Intervention techniques have had a poor success rate until the introduction of community participation that included populations which identified health issues and the subsequent courses of action (Puska, 2002). Switzerland and Finland display significant examples of such approaches in research targeting cardiovascular heart disease, when patients responded to being involved in public health planning, implementation and evaluation by reducing risk factors and levels of mortality due to heart disease (Puska, 2002). In California, the writing and distribution of the California Wellness guide at a grassroots level resulted in a high percentage of behavioral changes and the wider use of available facilities (Neuhauser, Schwab, Syme, Bieber, & Obarski, 1988). Korpela et al. (1998) discuss how one of the main components of success in a health project in Nigeria was that the community included their own needs in the design for the appropriate use of technology. In this example, the involvement of technology designers for local hospital information systems, and the health care workers that utilised the information systems, did not provide a large enough network to gain clinical benefit from information technologies. A workshop was designed to bring community members, health workers and information technicians together in a manner befitting local tradition so that all participants could define health needs, as well as better understanding how information technology could work towards alleviating concerns. In this manner, the information technology systems finally proved beneficial to the communities for whom they were designed.

Another example from Nairobi, Kenya, shows how 500 non-permanent families created an informal community and, with the help of local organisers who specialised in community development through empowerment, the community transformed itself into a formal society that was able to address subsistence and health care needs through grassroots initiatives (Macfarlane et al., 2000).

Prior research has suggested that formal participation in social planning contributes to lower mortality rates and improved perceptions of health (Young & Glasgow, 1998). Other researchers have shared evidence which supports these findings. In Finland, for example, individuals that contribute to strengthening a community have a greater sense of belonging and empowerment, resulting in heightened feelings of health (Hyypä & Mäki, 2003). Not only are needs better discerned and addressed through communities actively deciding for themselves, the resulting social capital and group cohesiveness contribute to actual indicators of health.

While definitions and utilisations of community involvement have varied throughout its application, the most successful cases have resulted from needs originating from populations and communities deciding on the resolution of health disparities. Once the need for grassroots planning and true community participation has been established, however, questions arise as to what exactly is meant by community and which individuals are given voice within the community forum.

**Heterogeneity in Communities**

Communities are not homogenous in nature. Age, gender, disability, socio-economic status and many other factors contribute to profound differences in health needs of individuals, as well as the level of involvement of groups (Wallerstein, 1992). This heterogeneity of populations must be considered when examining community participation, namely the question of representation within communities, barriers to participation for disenfranchised individuals and the effects of programmes that are imposed by one section of a community on other community members. It is important that all of these factors be considered, so that community participation results in existing needs being addressed, rather than the deepening of power disparities within populations (Morgan, 2001).

The basis for community development is to allow individuals, and therefore communities, to control and decide on the actions that affect their own health, thus bringing about empowerment (Zakus & Lysack, 1998). Wallerstein (1992) articulates that personal empowerment is intertwined with larger political structures comprised of economic control and power differentiation. An impediment to empowerment and successful community participation is over-relying on prominent community
members who, because of socio-economic advantages, have the time and income to participate and become involved (Botes & Rensburg, 2000). However, higher SES individuals, who have the time to become involved in endeavors such as attending planning meetings, might not be representative of the majority of a community (Zakus & Lyeack, 1998). Over-representation may result in a deepening of existing socio-economic divisions and power disparities when disenfranchised individuals do not have a chance to vocalise needs (Higgins, 1999).

**Barriers to community participation**

Many factors may contribute to more visible community members gaining disproportionate control of participation. The legitimisation of professionally based organisations rather than grassroots initiatives by international agencies or governments, can render disenfranchised populations even more silent (Boyce, 2001). Some agencies may target professionals or elites in order to gain compliance with top-down projects that might disproportionately benefit members of communities (Botes & Rensburg, 2000). Those in positions of power may resist any programmes that could threaten existing dynamics (Church et al., 2002). Service agencies might view beneficiaries of programmes as passive recipients of services and resist disenfranchised individuals’ presence in policy planning (Boyce, 2001). If only the portion of the population already in power is represented, then individuals that may have barriers to participation may be further discounted (el Ansari & Phillips, 2001). Community participation that is geared toward alleviating health concerns, then, will not reach the very populations that are most affected by health and power disparities. Lack of representation equals the lack of opportunity to build trust, feelings of community and, subsequently, empowerment (el Ansari & Phillips, 2001).

Barriers to participation are reported in numerous case studies discussing community involvement. These barriers primarily include the economic costs of devoting time to the ongoing involvement in programme planning along with the subsequent exhaustion that accompanies continued efforts to ensure economic stability. Many community members cannot afford to miss activities relating to economic survival (Whiteford, 1997). The most disenfranchised individuals in communities may be chronically exhausted from meeting life’s economic demands, and as such, participation in volunteer group activities might take a low priority. Transportation and child-care are also substantial costs for many individuals, and, without affordable and accessible accommodation, it becomes unlikely that community members will initiate or maintain participation in programme planning. Additionally, professionals may be paid to be involved in programme planning, while community members are not (Boyce, 2001). If community groups are not compensated for time, child-care, or cost of transportation, they are less likely to be involved in time-consuming activities such as planning meetings or programme reviews. Many disenfranchised individuals are, therefore, not given the forum in which to voice health care needs due to lack of access to planning procedures (Macfarlane et al., 2000).

Furthermore, existing feelings of disempowerment due to previously implemented top-down programs or socio-historical events may produce psychosocial barriers in the form of apathy and other hopeless feelings in individuals regarding matters of involvement (Boyce, 2001). In her study of dengue fever in the Dominican Republic, Whiteford (1997) discovered that when political and administrative bodies failed to fulfill promises of bringing education, waste disposal, potable water and health facilities to the community of Villa Francesa, individuals responded with a sense of hopelessness that affected illness-preventing activities. In South Africa, the legacy of apartheid resulted in large economic disparities, with the consequence of employment and adequate housing being difficult to obtain. This economic disenfranchisement, combined with histories of psychological abuse, led to feelings of powerlessness and subsequent disregard for the use of condoms among sex workers in an informal community in South Africa (Campbell & Mzaidume, 2001). Socio-historical and political factors created not only a physical barrier to participation, but a psychosocial one as well. This non-participation serves to compound and reinforce feelings of isolation and of being discounted, leading to further marginalisation (Higgins, 1999).

In the early 1980s, as organisations became more aware of the interconnectivity of health issues with larger socio-economic situations of populations, the
system of intersectoral collaboration was developed. This technique centered around organisations involved in the health sector coordinating with other government organisations or agencies grounded in agriculture, water treatment, development and education in order to ensure that all issues affecting health were addressed (De Kadt, 1982). However, research found that collaborative processes could still place decision-making power into the hands of professionals and international agencies, while the needs expressed by disenfranchised individuals remained unnoticed (Botes & Rensburg, 2000). All of the factors representing barriers to participation had still not been addressed. Korpela et al. (1998) articulate how it is important to assess the ramifications of policy on all affected individuals, not just the members that implement programmes.

Examining the effects of programmes suggests that the viewpoint of what is considered good policy should be taken into account. What is deemed beneficial for some in a heterogeneous society, might not be good for others. If a smaller group takes control of decision-making processes, it may well be at the expense of the larger community (Botes & Rensburg, 2000). Wallerstein (1992) discusses how, if one group benefits at the cost of another, power disparities deepen. Monopolisation by health professionals, wealthier individuals or a concentrated and powerful group within communities can endanger active participation by vulnerable or disadvantaged factions of populations (Botes & Rensburg, 2000). Campbell and Mzaldume's (2001) research in South Africa denotes that successful community participation is dependent on decision processes reaching all members of a community.

Although many texts discuss an already egalitarian society as ideal for community participation, this is not realistically the case in many communities. Korpela et al. (1998) believe, however, that, while organisational barriers, economic hardship and the general insecurity of life create obstacles to cooperation in developing countries, it is not totally impossible to overcome these obstacles. In fact, the building of social capital and empowerment may aid the removal of these barriers and contribute to a more cohesive community. Reliance on one faction of society to define public health needs and solutions assumes homogeneity of members, whereas genuine equality emerges from affirming, rather than dismissing, group differentiations. It is therefore necessary to engage all members of a society in community participation not only to discern public health needs, but also to encourage the building of social capital and empowerment through community cohesiveness. Increasing personal empowerment can contribute to heightened participation and an increase in involvement (Higgins, 1999; Parry et al., 2004).

When examining power disparities and barriers to participation in primary health care in South Africa, el Ansari and Phillips (2001) make recommendations for incorporating the needs of all individuals into health care initiatives. Since there is the necessity for joint decision-making to elevate the cohesion of the community, and the lack of flow of information between leaders and members may hinder collaboration, there is a direct need for communication to remove social barriers and stigmatisation. Many factors may enhance communication. Good leadership skills that display availability and approachability of leaders to community members, as well as the willingness of leaders to attend community forums, may increase feelings of equity within communities. The transparency of actions, motives and decisions are critical to ensure the confidence of community members toward leaders. Clearly delineated objectives of community organisations may contribute to feelings of understanding and empowerment by disenfranchised individuals.

Communication as a tool to remove barriers may also be used between disenfranchised individuals and professionals or bureaucrats. While lack of information may contribute to a disproportion of resources between members of communities and professionals, the broader dissemination of information may aid in the ability of disenfranchised individuals to voice their needs (Church et al., 2002).

It is essential that all groups in society are represented, especially marginalised populations. It is important that all groups are ensured a voice, even if it is dissenting, to make sure that individuals in need of care or services can articulate their specific needs (Korpela et al., 1998). All members should be targeted to ensure that one group is not
monopolising the decision-making process; that disadvantaged individuals can address socio-political and health needs, and that projects suggested by one group will not hurt or further disenfranchise another. With a firm grasp on levels of participation and having identified which members of communities need to be targeted for involvement, the last aspect to consider is how to facilitate community participation.

The Contextualisation of Community Participation and Guidelines vs. Blueprints

Contexts for community participation are socio-politically, historically, culturally and economically specific. Replication of projects based on the overgeneralised conception of developed communities or disenfranchised populations is problematic when applied to varying situations (Botes & Rensburg, 2000). The homogenising and overgeneralisation of poverty and illness contribute to the idea that populations can be named and described, with broad plans formulated for overall aid (Macfarlane et al., 2000). These labels should be removed to better see the perspectives and complexities of individual communities.

Contextualisation of community participation, therefore, suggests that there cannot be a static design of community participation (Morgan, 2001). Botes & Rensburg (2000) (in their discussion of community participation relating to development procedures) suggest the term "guideline" when discussing elements that may contribute to the success of participation. This terminology assumes that certain points may guide community participation but should be considered fluid guidelines for ethical conduct rather than concrete procedures for community participation. The guidelines for anyone involved in community participation practices cited by Botes & Rensburg (2000) are:

Demonstrate an awareness of... status as outsider to the beneficiary community and the potential impact of involvement
Respect the community's indigenous contribution as manifested in their knowledge, skills and potential.
Become good facilitators and catalysts... that assist and stimulate community-based initiatives and challenge practices which hinder people, releasing their own initiatives and realising their own ideals.

Promote co-decision-making in defining needs, goal-setting and formulating policies and plans in the implementation of these decisions. Selective participatory practices can be avoided when... workers seek out various aspects of interest, rather than listening only to a few community leaders and prominent figures.

Communicate both programme/project successes and failures - sometimes failures are more informative than successes.

Understand and derive inspiration from 'Ubuntu' - a Southern African concept encompassing key values such as solidarity, conformity, compassion, respect, human dignity and collective unity.

Listen to community members, especially the more vulnerable, less vocal and marginalised.

Guard against the domination of some interest groups or a small unrepresentative leadership clique...

Involve a cross-section of interest groups to collaborate as partners in jointly defining development needs and goals, and designing appropriate processes to reach these goals.

Acknowledge that process-related soft issues [community input and analysis] are as important as product-related hard issues [statistical measures of communities]. Any investment in shelter for the poor should involve an appropriate mix of technological and social factors, where both hardware and software are developed together. In this regard many scholars recognise the importance of a multi-disciplinary approach to project planning... The inclusion of a social scientist and someone with the appropriate skills within the community, to work together with planners... is very important. A multi-disciplinary approach will only succeed if technical professionals recognise and include the contributions of their social scientist partners in the planning process.

Aim at releasing the energy within a community without exploiting or exhausting them.

Empower communities to share equitably in the fruits of development through active processes whereby beneficiaries influence the direction of development initiatives rather than merely receiving a share of benefits in a passive manner.
In order to guarantee full empowerment of communities, however, ownership of projects, the delineation of needs and the assessment of solutions should remain in the hands of communities (Zakus & Lysack, 1998).

Conclusion
Since the solidification of the need for community participation at Alma Ata, many definitions and forms of community involvement have ensued. Discussions regarding the level of participation, the representation of individuals in communities and guidelines for involvement, have been numerous and in-depth. Scholars have advocated a reworking of top-down procedures to bottom-up initiatives to ensure empowerment and forums for communities to make their own decisions (Macfarlane et al., 2000). Communication between all factions of society must be employed to ensure full representation of marginalised members in decision-making processes (Whiteford, 1997; Zakus & Lysack, 1998). Last of all, community participation needs to be contextualised to populations, implying that there is no static procedure. It therefore stands to reason that true community participation is instigated and controlled by communities who are considerate of all groups within societies, including those with barriers to participation, and remain fluid to fit the needs of communities.

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References


