

Review article

Revisiting community participation

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Community participation in health is a complex entity that has been examined extensively in the literature and continues to be of great interest among community health workers. The genesis of the idea and its conceptual development are primarily attributed to large multinational health institutions, particularly the World Health Organization. However, the *implementation* of community participation is the ultimate responsibility of local health programme initiators. It is therefore at the local level where day to day realities of incorporating community participation into health service delivery are confronted. This paper reviews the value of community participation in health and provides a detailed examination of the challenges facing its implementation and sustainability. In 1978, the World Health Organization placed community participation squarely at the centre of their strategy to achieve *Health For All By The Year 2000*. As the year 2000 nears, it is time to critically re-examine the notion of community participation and the most pressing challenges to its viability.

Introduction

The idea of community participation in health first appeared in the early 1970s as it was becoming clear that the basic health needs in Southern countries could only be met through the greater involvement of local people themselves. The concept was formally articulated by the World Health Organization (WHO) at Alma-Ata in 1978, and was henceforth forged as the cornerstone of the strategy to achieve *Health For All by the Year 2000*; namely, primary health care (PHC).¹ This Declaration formally alerted nations worldwide that physician centred care and hospital based programmes were inadequate to achieve global health. Rather, attainment of good health was thought to centre on concepts with an underlying democratic vision – concepts like empowerment, health promotion, and collective action. With its campaign, the WHO and several of its member governments launched an unprecedented international revival of interest in wellness, prevention of illness, and local control of services to improve people's health. At the core of these efforts was community participation.

Once solidified in international health policy, many countries adopted community participation as the means by which to address important health problems. This is exemplified by national efforts to establish and strengthen mechanisms for community participation in health through social policy, legislation, and other public means.^{2–13} The essential question in 1997, however, is how successful have these efforts been. Nearly two decades after Alma-Ata, the strategy originally conceived as a commonsense and straightforward approach is recognized to be fundamentally more complex.

A myriad of difficulties confound those dedicated to global improvements in health. The purpose of this paper is to review the value of community participation and examine those problems which appear most intractable. Careful analysis of the international experience may provide much needed insight into community participation, and as such, may contribute to a firmer foundation for this much valued strategy.

Box 1. Factors leading to community participation in health

1. Recognition of the right and duty of people to participate in public and community affairs, including personal health.
2. Institutionalized health systems' inability to provide for all health related needs.
3. Recognition that planned social changes in health can only be achieved by focusing on the community as the major locus of attention.
4. Rising standards of living and increasing education levels, and an awareness of this among the poor, all leading to raised health expectations.
5. Diminished confidence in policies made solely by health experts, professionals, and program managers.
6. Concerns about the costs associated with health services and the best use of limited resources.
7. An increasingly elderly population with chronic and disabling conditions, while preventable communicable diseases continue to threaten large populations.
8. A perceived untapped resource of voluntary public input to improve health services, and the belief that such input can make a positive difference.

The value of community participation

Community or public participation in health, sometimes called citizen or consumer involvement, may be defined as the process by which members of the community, either individually or collectively and with varying levels of commitment: (a) develop the capability to assume greater responsibility for assessing their health needs and problems; (b) plan and then act to implement their solutions; (c) create and maintain organizations in support of these efforts; and (d) evaluate the effects and bring about necessary adjustments in goals and programmes on an ongoing basis.^{1,14-15} Community participation is therefore a strategy that provides people with the sense that they can solve their problems through careful reflection and collective action.^{3,7,16-17} While many individual factors contribute to the achievement of greater community participation in health (Box 1), collective wisdom holds that the core value of community participation is that it provides a mechanism for people to participate in activities that have the potential to impact positively upon their health.¹⁸⁻¹⁹

Reputed benefits

One of the most attractive aspects of community participation is its widely reputed health and social

benefits. While the health literature is seriously lacking in empirical studies that specifically demonstrate these benefits, it is widely accepted, based on theoretical grounds and personal experience, that it facilitates many positive outcomes.^{18,20-21}

Perhaps the most important benefit cited is the heightened sense of responsibility and conscientiousness regarding health and the concomitant gain in power achieved through the acquisition of new skills and control over resources.¹⁹⁻²² Participants have the opportunity to educate themselves to the possibilities of controlling their own destiny, often resulting in a more equitable relationship between the so-called clients or recipients of health services and the providers.¹⁴ A related benefit is the potential for greater diffusion of health knowledge in the community and greater use of indigenous expertise,²³ although achieving this goal is not easy.²⁴⁻²⁵ Another reported benefit of the additional training and experience acquired through participation in health initiatives is that it may enhance future employment opportunities,²⁶ although not all agree that jobs are likely to follow.²⁷⁻²⁸

The organization and delivery of health services are also reported to benefit from community

participation. It is argued that health services are provided at a lower cost, and added resources can be brought into the system, in part due to greater access to fundraising opportunities but more especially to the availability of volunteers.²⁹⁻³¹ Better determination of the need for health facilities, their location and size, the number and types of personnel required, recruitment procedures, as well as employment practices and personnel policies, are also expected. Equally important, it is believed that resources will be more often directed to the so-called 'felt needs' of those in the community, and that health activities will be carried out more appropriately when the community is given greater control.³¹⁻³² Greater local involvement is thought to decrease feelings of alienation on the part of the community and foster less authoritative relationships between the community and health officials. All of these benefits are believed, ultimately, to have a positive impact on health.

Problems with conceptualization and evaluation

The reputed benefits of community participation, however, are just that – reputed. What evidence is there that this ideal can be realized? Unfortunately, a number of significant difficulties loom in this regard which can be attributed to the following: (a) the great variety of health initiatives using community participation as a strategy; (b) the complexity of the community participation process; and most fundamentally, (c) what community participation itself is understood to mean.

In the first place, the manner in which community participation is expressed varies considerably with the context in which it is implemented. This makes the comparison of projects and their evaluation highly problematic. A related difficulty is determining the unique contribution of community participation to improvements in health. Disentangling the effects of local participation from other effects is a very complicated procedure. Despite these challenges, there is some level of agreement that a community's level of participation reflects the underlying level of power in its possession.³³⁻³⁷ Participation in health, therefore, can range dramatically – from relatively passive involvement in pre-determined activities, to full control of health organizations and health-related affairs.³⁸⁻⁴⁰ This diversity has significantly hampered efforts to investigate the value of community participation in health.

The second major problem is that, as a specific technique, community participation is not well understood. For example, although it is widely known that community participation is heavily reliant upon the commitment and active involvement of informal local leaders to whom others naturally turn for advice, support and leadership,^{3,13,41} it is far from clear what kinds of personal characteristics such health workers ought to have or what training they ought to receive to achieve the greatest effect.²⁸⁻⁴⁰

There are also innumerable difficulties that relate to the matter of community representation, although few may be immediately obvious. These issues come to the fore, however, when individuals get caught between conflicting personal, community, and health system agendas.⁴²⁻⁴⁵ Difficulties also arise when minority segments of the population do not share the same values and priorities as the dominant (or decision-making segments), or, for reasons of culture,^{25,38} gender,^{39,46-47} or socioeconomic status,^{24-25,28,34} they find it difficult to become involved. While some health experts believe the representativeness of the health worker holds the key to community participation success⁴⁸ others argue that the ideal of participation will only be achieved if health workers prove themselves capable of meeting the health needs of those they serve.⁴⁹ Thus, the operational aspects of community participation must be better understood before we can conclude that community participation can accomplish the health outcomes ideally envisioned.

The third major problem with community participation is that, despite its prominence as a guiding principle in international health policy, this concept has managed to elude significant critical analysis. As Jewkes and Murcott⁵⁰ and others⁵¹⁻⁵³ have recently observed, this lack of analysis coupled with its inherent conceptual ambiguity, underlies many of the failed expectations around community participation in health.

A contributing factor in this regard is that the traditional health literature has tended to confer 'community' status on families, ethnic groups, and neighbourhoods alike, and at other times, upon larger jurisdictions such as health districts and regions.^{13,54-55} But by blurring the two most basic aspects of community – community as geographical locale, and a sense of community generated on the basis of shared interests, values and identity⁵⁶⁻⁵⁸ – the analysis of community participation has been

substantially complicated. Lysack's recent analysis of the meaning of community in health is therefore a valued addition to the health literature.⁵⁹

In her analysis, Lysack reviews the sociological and historical origins of the idea of community and the rhetorical power of this persuasive word. Using rehabilitation as the context for her discussion, Lysack both here⁵⁹ and elsewhere,⁶⁰ demonstrates how the positive language of community elicits powerful images of a harmonious and equitable place where reciprocity and mutual concern prevail. When this is the case, all things 'community-based' are looked upon favourably, despite an absence of investigation of the actual features of those groups who are called, or call themselves, communities. Without investigating the basis for the assertion of community status, the language of community may disguise less genuine and egalitarian undertakings however. Lysack makes a compelling case that many of the difficulties confronted in the implementation of community-based disability projects can be traced to an inadequate conceptualization of community. Coupled with the additional challenges posed by the meaning of participation,⁶¹ community participation is a far more complicated idea and initiative than it appears at first, which in turn, hinders a final judgement with respect to the value of community participation overall.

Achieving community participation: experiences from the field

The previous sections of this paper briefly reviewed the value of community participation and identified the most significant difficulties relating to the evaluation of community participation. The remainder of the paper is devoted to an examination of the obstacles to community participation, drawing on examples from the authors' own programme and research experiences.

Preparing the ground

Community participation as a strategy is always applied within an environment that has already achieved a varying degree of definition. The extent to which this definition promotes the ideal of collective cooperation and recognizes the inherent capacity and right of individuals to make their own life decisions determines the ultimate success of community participation. A number of predisposing conditions favourable to community participation have been identified (Box 2). Most simply however, as

Bracht⁵³ states, there must be an accurate understanding of a community's needs, resources, social structure, and values, and early citizen involvement, in order to build collaborative partnerships and facilitate broad community participation.

Community participation also requires that a suitable formal organization (e.g. committee, board, coalition or network) be established and sustained. While there is no formula to guide this process, it is generally believed that such an organization should be developed with significant community input and have positive links with local political and government structures.^{8,14} The organization charged with implementing community participation activities must also be sensitive, open and knowledgeable about collaboration and coordination with other individuals and programmes,^{39-40,53,62-65} skills which, if not present initially, can fortunately be taught and learned.⁶⁶ Goals and expectations with respect to participation must also be mutually identified and accepted by all involved, because organizational structures, in themselves, cannot ensure community participation.^{13,28,59,67 70}

The composition of new community health organizations is an important component of organizational success and a range of mechanisms exists for its establishment: direct election from the population at large; election from specified interest groups; and secondment/appointment from local government, political parties or special interest groups. The responsibilities and powers of the various stakeholders must then be identified and accepted. This includes mechanisms for accountability as well as transparency regarding representation of individuals once selected, i.e. the degree of independence participants have from interest group policies. While formal legitimization by government is also often considered a necessity for community participation,^{65,70-72} the methods used to select organization members and the degree to which they represent local issues are obviously crucial in determining the perceived legitimacy of the representatives in the eyes of the population served.³⁴

Finally, there must be an investment in the training of new members of community organizations in the domains of health planning and other managerial tasks. Although the actual skills necessary are particular to each specific project, competency is generally required in five major domains: community organizing; problem solving and priority setting;

Box 2. Predisposing conditions for community participation in health

1. A political climate which accepts and supports active community participation and interaction at all levels of program development, implementation and evaluation.
2. A political context in which policy, legislation, and resource allocation take account of regional/local circumstances, aspirations and needs.
3. A sociocultural and political context which supports individual and collective public awareness, knowledge acquisition and discussion of issues and problems affecting individual and community well-being.
4. A political and administrative system which promotes and accepts decentralization and regional/local authority for decision-making on health policy, resource allocation and programs.
5. An acceptable universal level of availability and accessibility of health services for meeting basic health care needs on a systematic basis.
6. A health care delivery system in which institutions and professionals have experience with and are committed to a community orientation through such mechanisms as institutional boards, advisory groups, health committees, and community education programs.
7. A health care delivery system in which the institutions, service professionals and managers are flexible, genuinely committed and supportive, and have experience with attempting to respond to regional/local needs in collaborative and creative ways among themselves and with government.
8. Some experience in intersectoral activity of health services and professionals with related services such as water and sanitation, other public works, occupational health, agriculture, social services, housing, and the law.
9. A citizenry in possession of sufficient awareness of, and knowledge and skills in social organization and health related issues.
10. A community in which health is a priority issue and which demonstrates widespread interest in healthy lifestyles, fitness, nutrition, disease eradication and prevention, and a safe and healthy environment.
11. A community that is willing to collectively accept responsibility, and give their consent and commitment to community health initiatives.
12. A community with previous successful experience with community participation.
13. Responsible, responsive, and efficient media, information, and communication systems within and between communities and with various government levels.
14. For all concerned, the proposed participation must be perceived as meaningful and leading to prompt, visible results in addition to the achievement of important longer term goals.

health information collection and analysis; health intervention planning and delivery; and finally, programme evaluation.⁸ The individuals who participate also require on-going education and support.⁷² However, there are personal costs of time and sometimes income loss associated with participation which need to be taken into account, especially when individuals come from other than middle to upper socioeconomic groups.⁷³ Rewards for community participants are largely philosophical, emotional and symbolic as compared to health professionals and managers for whom participation often has tangible professional and career advantages.^{28,48-49} Thus, to be effective, community participation must address not only these personal resource implications, but also ensure that especially disadvantaged target groups are included in the process.^{15,27,42,53,74-76}

Community participation is a complex and fragile process, however, and while the measures outlined above can substantially increase the probability of success for a community health project utilizing a participatory approach, there are many factors that operate to diminish this success. Two of the most basic are the nature of actual communities themselves and the realities of collective human participation.

The nature of community

Communities are very heterogeneous entities, not only in their demographic composition, but also with respect to their interests and concerns. This diversity has a profound impact upon every step of the community participation process, and while there may be little disagreement about the desirability of community participation, the diversity of those groups called communities can create real problems for selection, representation and accountability of individuals.

First, determining who is a legitimate representative of the community is far from straightforward. People with sufficient health expertise who are also willing to donate the requisite time and energy to community-based health projects are not always easy to find. More fundamentally though, those who possess such expertise may be looked upon by the general population as elites – so different, in fact, that they are not supported by the public at large. When this is the case, then, intended or not, the dominant majority dictates the health agenda, with little or no meaningful input from those considered to be the target of community-based health interventions.⁴¹

Another set of problems arises when the minority group itself prefers not to engage actively in the participatory process. This paradoxical finding has been reported by Stone²⁴ who states that it is precisely the poor and disadvantaged who may discount participatory processes, instead preferring professional handling of community health matters. When disadvantaged minority groups are accustomed to being bypassed, or at most condescendingly solicited and then ignored, then it is hardly a surprise that they will have little interest in being involved.⁴²⁻⁴³

This avoidance of the participatory process has been observed in the international disability context where rural villagers have refused to participate in community-based rehabilitation (CBR) projects.⁷⁵⁻⁷⁶ While for the most part supportive of the ideal of these projects, research in Indonesia has shown that villagers are suspicious of community participation because they fear that the limited professional medical services they do have will be replaced with something less. In villages in Central Java, for example, this concern has taken two specific forms. Some fear that participation in CBR provides an excuse for local government to eliminate the local health centre and reduce funding for monthly public health nurse visits. Others fear any health gains accomplished via a community approach work against their larger purpose of petitioning the national government to increase both the amount and quality of government health care. The introduction of the CBR programme, reliant as it was on unpaid and lesser skilled volunteers, produced a trade-off that the Indonesian villagers were unwilling to make.

In this example, the project managers were challenged to demonstrate the value of their programme to the local population. In an interesting decision they chose to pay for a surgical correction of a young boy's club foot deformity (not exactly the typical style of a 'bottom-up' community development approach that CBR aims to be) in order to convince the village that action can be taken to improve the lives of people with disabilities. The investment 'paid off' in the sense that the village committed itself to the CBR programme. However, this situation raises a number of significant questions with respect to the long-term sustainability of health projects that lack the resources to deliver dramatic, visible results. Furthermore, few health problems are amenable to a 'quick fix', and there may be other serious drawbacks to generating community interest in this way.

A second major problem is that communities are rarely, if ever, a homogeneous whole. Many segments of the population can be isolated from mainstream political and social organizations, including the organizational structures of the health system. Hence, some groups within the so-called community will be unaware of opportunities for participation or find it hard to break into the system. This too has been observed in the disability context where negative attitudes toward people with disabilities, low levels of education, and other historical biases have prevented disabled people from participating in society and holding substantial political power.⁷⁷⁻⁷⁸

Even when relatively powerless groups do find ways to participate in the mainstream, not all sub-groups within them feel adequately represented. Official leaders and spokespersons of the disability rights movement, for example, continue to be challenged by their own membership for their inability or reluctance to extend a voice to those most disenfranchised; for example, to women with disabilities, ethnic minorities, the elderly, and those with cognitive disabilities. The critical issue for advocates of community participation is to examine much more carefully who it is that is included in the community (and thus community participation) and who is not.

The third problem relating to the nature of community revolves around the matter of representation itself. Who has the right to speak for 'the community'? Who are legitimate community representatives? As it pertains to the process of community participation, representation becomes an issue when community health workers need to be selected and when community leaders need to be identified. In both instances, individual prejudices, stereotypes, and social and political ideologies can create problems that seriously impair the ability to organize in pursuit of better health.^{30,65,79-81} For example, in many parts of South East Asia, where the wives of prominent local businessmen and government officials often serve as CBR cadres, real conflicts between the local agenda of disabled people and the policies of government have arisen.⁷⁶

Theoretically, when groups within a community lack the requisite skills or power to represent themselves, efforts to increase their abilities in this area can be undertaken. In the interim however, determining how so-called community needs are identified and how solutions to them are identified continue to pose two of the most serious challenges to community

participation in health. The ultimate trick, as Walzer⁸² succinctly puts it, is 'to find ways of providing for needy members because of their neediness in a way that does not undermine their status as members of society' (p. 522).

The nature of participation

Like the concept 'community', participation has proven difficult not only to define but to practically initiate and sustain.^{25,38,61} There are a variety of reasons why this is so. One of the most obvious is that health initiatives reliant on public participation often place an additional burden on already disadvantaged individuals and groups.⁸³⁻⁸⁴ There are important costs involved in participatory activities, including personal time expenditures, training costs, and information compilation and dissemination costs, and all are ongoing and subject to peaks of demand. However, unless they are taken into account, only the most privileged segments of society participate, thereby excluding and possibly worsening conditions for lower income citizens. For women in Southern countries in particular, as the traditional caregivers of the infirm, this has real and profound implications for the health of the community.^{46,73,85-86} Unless participation is carefully developed to take these issues into account, few may be willing to be actively involved or involved for very long.

Second, community participation comes in a variety of forms, and if health projects recognize only some forms as valuable, there will undoubtedly be problems. For example, health professionals tend to involve themselves at the formal organizational level, and tend to contribute and recognize specialized medical knowledge as a priority in decision-making.^{23,25,87} Lay participants, on the other hand, tend to play a more 'hands-on' role in the actual delivery of community-based health services, and usually assess the value of projects in terms of their practicality and usefulness.

There is literature to suggest that targeting project objectives as specifically as possible will lead to greater community cohesion around an issue, which, in turn, increases the likelihood of success.⁸⁸ However, other research indicates that when ordinary individuals participate alongside health professionals and project managers, those with intimate knowledge of the system and the greatest professional prestige will have a greater impact on the process than their numbers might otherwise suggest.⁸⁵⁻⁹³ The proper conclusion, then, is that all participation is not created

equal, and it does not inevitably lead to influence. For example, consumer board members have been shown to possess significantly less influence in decision-making than health care provider members, even though virtually no difference exists between the two groups' levels of participation.⁹⁴ Thus, even quite unintentionally, community participation usually ends in consolidating the power of professionals, rather than achieving the ideal of broad-based local involvement.⁹⁵⁻⁹⁶

In related work, researchers in the United Kingdom have further shown that even the most committed community health activists will eventually be criticized by their own constituency for appearing to be too closely allied with the health service managers.^{86,88-90} Indeed, the issue of balance of power within communities and within community organizations is a troubling one. Too often, genuine and balanced community participation only takes place at the operational stages of programme development. As a result, there will be charges of 'tokenism' and threats to withdraw from the participation process entirely. Managing the ensuing situation is yet another serious challenge to achieving the ideal of community participation in health.

In addition to the burdens that can be imposed by community participation and the difficulties in achieving broad and genuine local involvement, meaningful participation brings socio-political risks and implications.^{8,51,97-99} For example, there may be political and bureaucratic unwillingness to encourage widespread community participation since it may be perceived as a threat to established power patterns and actively resisted.^{14,33,80-81} The underlying purpose for community participation in health may also be viewed differently by these two groups. Governments may, for example, view community participation primarily as a means for legitimizing public policy and quickening the pace of project implementation, or alternatively, as a means for diffusing public criticism and delaying action.^{8,30-33,79-80} Community members, on the other hand, may view community participation as an opportunity to obtain direct power separate from, parallel to, or even in opposition to, the main political/government system.^{3,96,98} Thus, pre-existing tensions between segments of the population may be exacerbated, and not ameliorated, by an emphasis on community participation.

Community participation, empowerment and health promotion

No consideration of community participation in health would be complete without at least a brief analysis of its relation to empowerment and health promotion. While a complete review of these literatures is beyond the scope of this paper, it should be recognized that, fundamentally, it is the positive features thought to be associated with these approaches that have rendered them so attractive.⁸⁸ Unfortunately, as Wallerstein¹⁰⁰ notes, the conceptualization of empowerment and participation in health has left much to be desired. For instance, Wallerstein asks: Who exactly is empowered anyway – communities or individuals? And furthermore, does empowerment mean that some individuals or groups gain at the expense of others? Finally, does empowerment and health promotion sufficiently challenge power structures that systematically operate to leave some people in poorer health than others? Are health promotion and empowerment strategies, *in practice*, really more than rhetoric?

The historical origins of community empowerment rest with grassroots development projects which perpetuated the idea that empowerment consists of fundamental struggle with powerful groups such as governments who systematically oppress less powerful groups such as the poor and the illiterate.¹⁰¹ Health promotion, too, has strong roots in a social philosophy that asserts that the causes of ill health are largely attributable to adverse social conditions, not to insufficient medical care.¹⁰² Once again, however, we must ask whether either of these strategies have achieved their ideal.

In theory and in practice, empowerment and health promotion have been sharply criticized. In the first place, empowerment and health promotion efforts have been criticized for failing to adequately address equity and social justice concerns.⁹⁵ Second, and as discussed above, the structures and traditions of the formal health system often present major obstacles to meaningful involvement in health promotion and community empowerment activities.^{8,65,68,99} Third, there is the real question of whether all communities have the interest and capacity to contribute to community participation, even if they want to.¹⁰³⁻¹⁰⁷ Do we know, for example, whether concern for others is always present in the community? Furthermore, is it possible that other priorities displace health on the community's agenda? In contexts where the basic

physical necessities of life are lacking, or where the political situation precludes genuine community participation, it is incumbent upon the proponents of community participation to examine how relevant, or even possible, collective action is under such constraints.

The final problem is that at their core, health promotion and empowerment strategies may be at odds with the notion of community.¹⁰¹ As Riger so perceptively asks: 'Does empowerment of disenfranchised people and groups simultaneously bring about a greater sense of community and strengthen the ties that hold our society together, or does it promote certain individuals or groups at the expense of others, increasing competitiveness and lack of cohesion?' (p. 290). Because health promotion and empowerment strategies stress the development of new advocacy skills and social activism, the essence of these approaches is autonomy and conflict. But the essence of community is cooperation, communion and connectedness. Thus, situations which foster assertive self-determination (health promotion and empowerment strategies) may be the opposite of those which foster community cohesion.

This is rather troubling news for those dedicated to community empowerment, health promotion and community participation.¹⁰⁸⁻¹⁰⁹ It may however, at least in part, explain the drive in individuals to be part of a community (to be empowered) and the apparent fragmentation and divisiveness of communities in contemporary times (because of competition between communities). This issue aside, we are nonetheless returned to the throes of a familiar dilemma, that is, seeking to facilitate improvements in the health of disadvantaged groups without diminishing their inherent right to self-determination. Virtually every 'community-based' health project will confront this dilemma at some point in time. And while control by powerful interests is not the ideal of community participation and has been seen to be a liability in community health projects, there are occasions when such support is crucial. For example, the experience in Mexico has shown that government financial support to fledgling community organizations is essential, not only for the resource, but also for the official recognition it confers. The formal endorsement of medical professionals was similarly required, otherwise the programmes and referral systems operated much less smoothly, and intersectoral cooperation at all levels was poor.^{21,30-31} Without medical doctors who retained

highly visible leadership positions, the long-term viability of the Mexican project would have been left in considerable doubt.

Conclusion

In summary, to be both effective and long lasting, community participation must become a successful and integral part of the entire community's common experience and not remain as a structure imposed from outside.^{30-32,68} It must be rooted in the expectations of the community, supported by ongoing access to needed and usable information and to significant commitment of organizational staff and material resources, and be given genuine support by health professionals and managers, and by the political/administrative system. Perhaps more importantly though, a much better understanding of the nature of community and the nature of human social interaction and community participation must be gained. As this examination of community participation has demonstrated, this is likely to remain a challenging task. That is not to say that there has been no progress, for new methods are constantly being devised to study community participation. MacCormack¹¹⁰ has systematized a model for studying women's participation in health, Yach¹¹¹ has stressed the need for an increased application of qualitative approaches in community health research and demonstrated their value, and Boyce¹¹² and Rifkin et al.¹¹³ have proposed new conceptual frameworks within which to measure participation. But will new and better methods of community participation emerge from these evaluative efforts? And to what extent will the lessons learned in the course of two decades of institutionalized community participation in health significantly influence the field?

New problems will continue to arise in community participation as communities are dynamic and ever evolving entities. Our best preparation for the next millennium is to critically examine the history of community participation and continue to study its complex nature. Project implementation is unique at the local level and variations in implementation strategies bring increased opportunities to learn. Hence, more experimentation on both small and large scales, and an increased sharing of experiences, both positive and negative, are needed to maximize the potential of community participation – a much valued strategy in pursuit of Health for All.

References

- 1 Primary Health Care: A Joint Report by The Director-General of the WHO and The Executive Director of the United Nations Children's Fund on the International Conference on Primary Health Care in Alma-Ata, USSR, 6-12 September, 1978. New York/Geneva: WHO, 1978.
- 2 *Targets For Health For All*. Geneva: WHO, 1985.
- 3 *Health for All by the Year 2000: Strategies*. Washington, DC: Pan American Health Organization (PAHO), 1980.
- 4 Epp J. *Achieving Health For All: A Framework for Health Promotion*. Ottawa, Canada: Ministry of Supply and Services, 1986.
- 5 Evans J. *Towards a Shared Direction for Health in Ontario*. Report of the Ontario Health Review Panel. Toronto: Government of Ontario, 1987.
- 6 Lalonde M. A New Perspective on the Health of Canadians - A Working Document. Ottawa, Canada: Ministry of Supply and Services, 1974.
- 7 *Ottawa Charter For Health Promotion*. Ottawa, Canada: WHO/Health and Welfare Canada/Canadian Public Health Association, 1986.
- 8 *Community Participation in Health and Development in the Americas - An Analysis of Selected Case Studies*. (Scientific Publication No. 473). Washington, DC: PAHO, 1984.
- 9 Pedalini L, Dallari S, Barber-Madden R. Public health advocacy on behalf of women in Sao Paulo: Learning to participate in the planning process. *J Public Health Policy* 1993; **14**(2): 183-97.
- 10 Scepun O. Development and implementation of the Health for All strategy in the USSR. *Health Promot* 1988; **3**(3): 299-305.
- 11 Skupnjak B. *Community Participation Case Study: Yugoslavia*. Zagreb: Centre for Health Cooperation with Non-Aligned and Developing Countries. (WHO - ICP/PHC 0132), 1983.
- 12 Spasoff R. *Health For All Ontario - Report of the Panel on Health Goals for Ontario*. Toronto: Ontario Ministry of Health, 1987.
- 13 Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986.
- 14 Vuori H. Community participation in primary health care - A means or an end. In: Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986, pp. 1-17.
- 15 *Community Involvement in Health Development: Challenging Health Services*. Technical Report Series 809. Geneva: WHO, 1991.
- 16 McKnight J. Regenerating community. *Soc Policy* 1987; Winter: 54-8.
- 17 Hawe P. Capturing the meaning of 'community' in community intervention evaluation: Some contributions from community psychology. *Health Promot Int* 1994; **9**: 199-210.
- 18 Annett H, Nickson P. Community involvement in health: Why is it necessary? *Trop Doct* 1991; **21**: 3-5.
- 19 Dujardin B. Health and human rights: The challenge for developing countries. *Soc Sci Med* 1994; **39**(9): 1261-74.
- 20 Oakley P. *Community Involvement for Health Development: An Examination of the Critical Issues*. Geneva: WHO, 1992.
- 21 Zakus D. La Participacion Comunitaria en los Programas de Atencion Primaria a la Salud en el Tercer Mundo (Community Participation in Third World Primary Health Care Programs). *Salud Publica de Mexico* 1988; **30**(2): 151-74.
- 22 Schaffer R. Balanced participation in development. *Trop Doct* 1991; **21**: 73-5.
- 23 White A. Why community participation? A discussion of the arguments. *Assign Child* (Special Issue on Community Participation) 1982; **59/60**: 17-34.
- 24 Stone L. Primary health care for whom? Village perspective from Nepal. *Soc Sci Med* 1986; **22**(3): 293-302.
- 25 Woelk G. Cultural and structural influences in the creation of and participation in community health programs. *Soc Sci Med* 1992; **35**(4): 419-24.
- 26 Miliio N. Dimensions of consumer participation and national health legislation. *Am J Public Health* 1974; **64**(4): 357-63.
- 27 Lysack C, Krefling L. Community-based rehabilitation cadres: Their motivation for voluntarism. *Int J Rehabil Res* 1993; **16**: 133-41.
- 28 Robinson S, Larsen D. The relative influence of the community and the health system on work performance: A case study of community health workers in Columbia. *Soc Sci Med* 1990; **30**(10): 1041-48.
- 29 Martin P. *Community Participation in Primary Health Care*. Washington, DC: American Public Health Association, 1983.
- 30 Zakus D. The Effects of Resource Dependency and Community Participation on the Organization of Primary Health Care Services in the State of Oaxaca, Mexico. Unpublished doctoral dissertation, University of Toronto, Canada, 1992.
- 31 Zakus D. Resource dependency and community participation in primary health care. *Soc Sci Med* 1997; in press.
- 32 Nichter M. Project community diagnosis: Participatory research as a first step toward community involvement in primary health care. *Soc Sci Med* 1984; **19**(3): 237-52.
- 33 Werner D. Extension of the status quo or grassroots transformation? *Int Rehabil Rev* 1988; December: 5.
- 34 Green R. Politics, power and poverty: Health for all in 2000 in the Third World? *Soc Sci Med* 1991; **32**(7): 745-55.
- 35 Whitehead M. The concepts and principles of equity and health. *Int J Health Serv* 1992; **22**(3): 429-45.
- 36 Arnstein S. A ladder of citizen participation. *Am Inst Planners J* 1969; **35**: 216-24.
- 37 Feuerstein M. Rural health problems in developing countries: The need for a comprehensive community. *Com Dev J* 1976; **11**(1): 38-52.
- 38 Stone L. Cultural influences in community participation in health. *Soc Sci Med* 1992; **35**(4): 409-17.
- 39 Rifkin S. *Community participation in maternal-child health/family planning programs: An analysis based on case study materials*. Geneva: WHO, 1984.
- 40 Rifkin S. The role of the public in the planning, management and evaluation of health activities and programs, including self-care. *Soc Sci Med* 1981; **15A**: 377-86.
- 41 Tchamov K. Bulgaria. In: Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986, pp. 18-31.
- 42 Berman P, Gwatkin D, Burger S. Community-based health workers: Head start or false start towards health for all? *Soc Sci Med* 1987; **25**(5): 443-59.
- 43 Christensen P, Karlqvist S. Community health workers in a Peruvian slum area: An evaluation of their impact on health behaviour. *Bull Pan Am Health Organ* 1990; **24**: 183-96.
- 44 Reis T, Elder J, Satoto M, Sodjat B, Palmer A. An examination of the performance and motivation of Indonesian village health volunteers. *Int Q Commun Health Educ* 1990; **11**: 19-27.

- 45 Walt G, Perera M, Heggenhoughen K. Are large-scale volunteer community health worker programs feasible? The case of Sri Lanka. *Soc Sci Med* 1989; **29**: 599-608.
- 46 Mosse D. Authority, gender and knowledge: Theoretical reflections on the practice of participatory rural appraisal. *Develop and Change* 1994; **25**: 497-526.
- 47 Parpart J. Who is the 'other'? A postmodern feminist critique of women and development theory and practice. *Develop and Change* 1993; **24**: 439-64.
- 48 Paap W. Consumer-based boards of health centers: Structural problems in achieving effective control. *Am J Public Health* 1978; **68**(6): 578-82.
- 49 Jonas S. Limitations of community control of health facilities and services. *Am J Public Health* 1978; **68**(6): 541-43.
- 50 Jewkes R, Murcott, A. Meaning of community. *Soc Sci Med* 1996; **43**(4): 555-63.
- 51 Madan T. Community involvement in health policy: Socio-structural and dynamic aspects of health beliefs. *Soc Sci Med* 1987; **25**(6): 615-20.
- 52 Godbout J. Is consumer control possible in health care services? The Quebec case. *Int J Health Educ* 1981; **11**(1): 151-67.
- 53 Bracht N (ed). *Health Promotion at the Community Level*. Newbury Park, CA: Sage, 1990.
- 54 Brown I. Community and participation for general practice: Perceptions of general practitioners and community nurses. *Soc Sci Med* 1994; **39**(3): 335-44.
- 55 Nuyens Y. Health sector structures: The case of Belgium. *Soc Sci Med* 1986; **22**(2): 223-32.
- 56 Bell C, Newby H. *Community Studies: An Introduction to the Sociology of Local Communities*. London: George Allen and Unwin, 1971.
- 57 Butchart A, Seeday M. Within and without: Images of community and implications for South African psychology. *Soc Sci Med* 1990; **31**(10): 1093-102.
- 58 Hawe P. Capturing the meaning of 'community' in community intervention evaluation: Some contributions from community psychology. *Health Promot Int* 1994; **9**(3): 199-210.
- 59 Lysack C. Critical reflections on the meaning of community. *ACTIONAID Disability News* 1996; **7**(2): 43-47.
- 60 Lysack C. (Re)requesting Community: A Critical Analysis of the Idea of Community in the International Discourse of Disability Rights and Community Based Rehabilitation. Unpublished doctoral dissertation, University of Manitoba, Winnipeg, Canada, 1997.
- 61 Brownlea A. Participation: Myths, realities and prognosis. *Soc Sci Med* 1987; **25**(6): 605-14.
- 62 Boot J. The Netherlands. In: Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986, pp. 74-88.
- 63 Boot J. *Community participation in primary health care: The development of consumer participation in the Netherlands*. Utrecht: The Institute for Hospital Sciences, State University, Utrecht, 1983.
- 64 Chesney J. Citizen participation on regulatory boards. *J Health Polit Policy Law* 1984; **9**(1): 125-35.
- 65 Nichter M. The primary health center as a social system: PHC, social status, and the issue of team-work in south Asia. *Soc Sci Med* 1986; **23**(4): 347-55.
- 66 Pateman C. *Participation and Democratic Theory*. Cambridge: Cambridge University Press, 1970.
- 67 Fonaroff A. *Community Involvement in Health Systems For Primary Health Care*. Geneva: WHO, 1983.
- 68 Foster G. Bureaucratic aspects of international health agencies. *Soc Sci Med* 1987; **25**(9): 1039-48.
- 69 Healthy Toronto 2000 - A Discussion Paper. Toronto: Healthy Toronto 2000 Subcommittee, Board of Health, City of Toronto, 1987.
- 70 Schacht P, Pemberton A. What is unnecessary surgery? Who shall decide? Issues of consumer sovereignty, conflict and self-regulation. *Soc Sci Med* 1985; **20**(3): 199-206.
- 71 Zakus D. The Effects of Resource Dependency and Community Participation on the Organization of Primary Health Care Services in the State of Oaxaca, Mexico. Unpublished doctoral dissertation, University of Toronto, Canada, 1992.
- 72 Whyte A. *Guidelines for planning community participation in water supply and sanitation projects*. Geneva: WHO, 1983.
- 73 Lysack C, Krefling L. The myths of voluntarism and the women who make community based rehabilitation work. *CBR News* (London, England) 1994; **17** (May-August): 5.
- 74 *Global Strategy for Health for All by the Year 2000*. (Health for All Series No. 3). Geneva: WHO, 1981.
- 75 Lysack C. Some perspectives on the disabled consumers' movement and community based rehabilitation in developing countries. *ACTIONAID Disability News* 1996; **7**(1): 5-9.
- 76 Lysack C. Community participation and community-based rehabilitation: An Indonesian case study. *Occup Ther Int* 1996; **2**: 149-65.
- 77 Balcazar F, Seekins T, Fawcett S., Hopkins B. Empowering people with physical disabilities through advocacy skills training. *Am J of Comm Psych* 1990; **18**: 281-96.
- 78 Driedger D. *The last civil rights movement: Disabled Peoples' International*. New York: St. Martin's Press, 1989.
- 79 Rifkin S. Primary health care in southeast Asia: Attitudes about community participation in community health programs. *Soc Sci Med* 1983; **17**(19): 1489-96.
- 80 Collins C. Decentralization and the need for political and critical analysis. *Health Policy Plan* 1989; **4**(2): 168-71.
- 81 Collins C, Green A. Decentralization and primary health care: Some negative implications in developing countries. *Int J Health Serv* 1994; **24**(3): 459-75.
- 82 Williams G. Disablement and the ideological crisis in health care. *Soc Sci Med* 1991; **32**(4): 517-24.
- 83 Labonte R. Community empowerment: The need for political analysis. *Can J Public Health* 1989; **80**: 87-8.
- 84 Hamburg D. Habits for health. *World Health Forum* 1987; **8**: 9-12.
- 85 Minkler M. Ethical issues in community organization. *Health Educ Monogr* 1978; **6**(2): 198-210.
- 86 Berry L. The rhetoric of consumerism and the exclusion of community. *Com Dev J* 1988; **23**(4): 266-72.
- 87 Powell, M. *Fostering Community Participation Literature Review - Draft Interim Report*. Canadian Council on Social Development, Ottawa, 1987.
- 88 Levitt R. United Kingdom. In: Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986, pp. 89-100.
- 89 Community health councils: A chance to take stock. Editorial. *Lancet* 1980; July 19: 130-31.
- 90 Van den Heuvel W. The role of the consumer in health policy. *Soc Sci Med* 1980; **14A**: 423-26.
- 91 McComas J, Carswell A. A model for action in health promotion: A community experience. *Can J Rehab* 1994; **7**: 257-65.

- ⁹² Saint-Germain M, Bassford T, Montano G. Surveys and focus groups in health research with older Hispanic women. *Qual Health Res* 1993; **3**(3): 341-67.
- ⁹³ Grace V. The marketing of empowerment and the construction of the health consumer: A critique of health promotion. *Int J Health Serv* 1991; **21**(2): 329-43.
- ⁹⁴ Steckler A, Dawson L, Dellinger N, Williams A. Consumer participation and influence in a health systems agency. *J Comm Health* 1981; **6**(3): 181-93.
- ⁹⁵ Stevenson H, Burke M. Bureaucratic logic in new social movement clothing: The limits of health promotion research. *Can J Public Health* 1992; **83** (Supplement 1): 47-57.
- ⁹⁶ O'Neill M. Community participation in Quebec's health system: A strategy to curtail community empowerment. *Int J Health Services* 1992; **22**(2): 287-301.
- ⁹⁷ Hastings J. An analysis of the country studies: Lessons learned. In: Vuori H, Hastings J (eds). *Patterns of Community Participation in Primary Health Care*. Copenhagen: WHO Regional Office for Europe, 1986, pp. 124-33.
- ⁹⁸ Rifkin S. Health planning and community participation. *World Health Forum* 1986; **7**: 156-63.
- ⁹⁹ Justice J. *Policies, Plans, & People*. Los Angeles, CA: University of California Press, 1986.
- ¹⁰⁰ Wallerstein N. Powerlessness, empowerment, and health: Implications for health promotion programs. *Am J of Hlth Prom* 1992; **6**: 197-205.
- ¹⁰¹ Riger S. What's wrong with empowerment. *Am J of Comm Psych* 1993; **21**: 279-92.
- ¹⁰² Popay J, Williams G. Public health research and lay knowledge. *Soc Sci Med* 1996; **42**(5): 759-68.
- ¹⁰³ Pilisuk M, McAllister J, Rothman J. Coming together for action: The challenge of contemporary grassroots community organizing. *J Soc Issues* 1996; **52**(1): 15-37.
- ¹⁰⁴ Ife J (ed). *Community development: Creating community alternatives - vision, analysis, and practice*. Sydney, Australia: Longman, 1995.
- ¹⁰⁵ Rissel C. Empowerment: The holy grail of health promotion? *Hlth Prom Int* 1994; **9**: 39-45.
- ¹⁰⁶ Dinkel N, Zinober J, Flaherty E. Citizen participation in CMCH program evaluation: A neglected potential. *Community Ment Health J* 1981; **17**(1): 54-65.
- ¹⁰⁷ Crawshaw R, Garland M, Hines B, Lobitz C. Oregon health decisions: An experiment with informed community consent. *JAMA* 1985; **254**(22): 3213-16.
- ¹⁰⁸ Rosenau P. Health politics meets post-modernism: Its meaning and implications for community health organizing. *J of Hlth Politics, Policy and Law* 1994; **19**: 303-33.
- ¹⁰⁹ Young I. The ideal of community and the politics of difference. In: Nicholson L (ed). *Feminism/Postmodernism*. New York: Routledge, 1990, pp. 300-23.
- ¹¹⁰ MacCormack C. Planning and evaluating women's participation in primary health care. *Soc Sci Med* 1992; **35**(6): 831-37.
- ¹¹¹ Yach D. The use and value of qualitative methods in health research in developing countries. *Soc Sci Med* 1992; **35**(4): 603-12.
- ¹¹² Boyce W. Evaluating participation in community programs: An empowerment paradigm. *Can J Prog Eval* 1993; **8**(1): 89-102.
- ¹¹³ Rifkin S, Muller F, Bichman W. Primary health care: On measuring participation. *Soc Sci Med* 1988; **26**(9): 931-40.

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