

# **Translating Rhetoric to Reality: A review of community participation in health policy over the last 60 years**

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## **Introduction**

The global dialogue around policies for health today places much discussion on the need for community participation for health improvements among populations. Participation is not only promoted in the context of provision and utilization of health services. Advocates also highlight participation as a key factor in the wider context of importance of social determinants of health and health as a human right (WHO, 2008b). Despite the growing interest in the role of participation, there is little concrete evidence that links participation directly to better health (Rifkin, 2009). The absence of this link continues to be a barrier to gaining full support of governments, funding agencies and health professionals to promote this concept. (Atkinson, 2011) The purpose of this paper is to review the evolution of advocacy for community participation as a key component of health policy over the last 60 years and to discuss the challenges of translating the rhetoric of participation into the reality of a sustainable contribution to health improvements.

## **Evolution of Community Participation for Health Policy**

Participation of community people in health care is not new. An obvious example is the participation of lay/community people providing care to family and community in their own cultural settings. In addition community lay people have been involved in the delivery of allopathic health services for the last one and a half centuries. One experience is the experiment of the Rockefeller Foundation in Ding Xian China in the 1920s where local people helped deliver services in an area lacking doctors trained in Western medicine. (Chiang, 2001) King also records similar experiences in Africa using locals as doctor's assistants (King, 1966) in colonial Africa. The popularity of this approach was promoted by the experiences of the so-called Barefoot Doctor, local

community people trained in basic health care and community mobilization in Maoist China in the 1960s. (Sidel and Sidel, 1983)

However, with the acceptance of Primary Health Care (PHC) as the official policy of the member states of the World Health Organization (WHO) in the Alma Ata Declaration in 1978, community participation entered the global health policy arena. Primary Health Care was defined as;

essential health care based on practical, scientifically sound and socially acceptable methods and technology made ***universally accessible*** to individuals and families in the community through their ***full participation*** and at a cost that the community and country can afford to maintain at every state of their development in the ***spirit of self-reliance*** and ***self-determination***. It forms an integral part both of the country's health system, of which is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and community with the national health system bring health care as close as possible to where people live and work and constitutes the first element of the continuing health care process. (WHO,1978 p.3-4)  
(Italics and bold Added)

The definition highlights community participation and equity as key principles of PHC.

The adoption of the Alma Ata Declaration almost immediately triggered a reaction that became a defining element of global health policy that is still relevant today. In an article in the New England Journal of Medicine, Walsh and Warren argued that while the vision and values of PHC were unquestionable, the translation of policy into practice needed refining. (Walsh, and Warren, 1979) They put forward a concept of "Selective Primary Health Care" (SPHC) focusing implementation of the policy on those diseases which had the highest prevalence and morbidity, had the highest risk of mortality and had the greatest possibility of control in terms of cost and effectiveness of the intervention. Rejecting the wider paradigm of health as holistic and also

reflective of social justice and social determinants, SPHC espoused view of health as dependent on care delivery as a vertical program. It challenged the alternative of comprehensive/horizontal approaches to health improvements of which community participation was a key component. (Rifkin and Walt, 1986)

As the theoretical debate on policy continued, several governments took up the challenge of implementing PHC on by creating national Community Health Worker programs (CHW). India, Sri Lanka, Botswana and Columbia all introduced CHWs as a commitment to the PHC policy. One result was during this period PHC was defined as CHWs. (Mburu, 1994) However these programs did not last long. Issues around selection, training and supervision arose. More importantly, questions about incentives and possible Government employment undermined these initial efforts. (Walt, 1990)

Implementing PHC during the period of the 1980's and 1990's presented major challenges. PHC, originally seen as low cost in fact demanded resources to expand rural services, meet the needs of the urban poor and support CHWs. The oil crises tightened many national governments' sources of income including financial support of the industrialized countries for the developing countries. In addition, many developing countries had financial budgets which undercut domestic spending in order to service debt repayments. Donor nations and the International Monetary Fund demanded debt restructuring by reducing country funding for social services including health and education. (Mohan et. al. 2000)

This shift in government financing was supported by the ascending neo-liberal view of economic development and the focus for health system reforms in the framework of the "new public administration". The arguments in this context called for a support of a market economy and a reduction of the size of the state. (Kaul, 1977) In health policy, the World Bank published its 1993 report entitled "Investing in Health", its first annual report to focus on one economic sector. The Report argued for a model of health care delivery based state provision of basic health care packages and private provision for services

outside the package. (World Bank, 1993) The Report did not once mention PHC. It marked a shift of the global policy dominance in the field of health from WHO to the World Bank.

In this period, UNICEF which co-sponsored the Alma Ata meeting with WHO and had a broader social development mandate continued to seek ways of supporting community participation. The Bamako Initiative focused on giving kits of basic drugs to rural health centres in developing countries as an incentive to sell these drugs and gain funds for wider community development. It promoted the “voice” of local people as members of health committees to oversee this program. (Mehora and Jarrett, 2002). Plagued by poor local infrastructure, corruption and variable government support, the Initiative had little universal acceptance. (McPake, 1993)

By the end of the 1990s, however, the World Bank responded to increasing evidence that it was more important to address issues around poverty reduction than to pursue strictly economic goals. The World Bank Report 2000 brought policy back to a focus on people by highlighting empowerment and social determinants including health, nutrition and education as key to improving life in poor areas world wide. (World Bank, 2000) Supporting this change of direction, the UN issued a declaration asking nations to meet the Millennium Development Goals (MDG), target oriented achievements that combined health status outcomes with wider development programs including eradicating hunger, achieving universal education, promoting gender equality and empowering women, ensuring environment sustainability, and developing a global partnership for development. (MDG, 2000)

The Millennium marked a paradigmatic shift in the way in which policy makers addressed health improvements (Rifkin and Bhatia, in press) The shift focused on recognizing health improvements as a result of social and environmental factors and not only of technical factors of bio-medical interventions and economic models. While the dominance of health professionals trained in the science of medicine remained, there was a growing demand to pay attention to social determinants of health and to the

wants and needs of beneficiaries of health care. Two documents published in 2008 by the World Health Organization provide evidence of this shift. The first was the World Health Report entitled “Primary Health Care: More Now than Ever”. (WHO 2008a) It promoted the return to the values and vision of the Alma Ata Declaration including putting people at the centre of health care improvements. The second was the Report of the Commission on the Social Determinants of Health (WHO 2008b), a commission established by WHO in 2005, to examine this topic composed of a broad range of experts from a variety of disciplines and countries. This Report argued for the recognition of the relationship between health status and determinants including, education, employment practices, universal health care, peoples’ ability to make choices and good governance based on extensive research. Many of these factors had been identified in Alma Ata but lacked supporting evidence.

It would be incorrect to say that these documents produced an overall consensus about how health improves. What they did do was provoke an arena for further debate on these issues. The debate continued within WHO itself. The organization now saw a rising tension about its priorities. Staff struggled to combine the traditional focus on health service provision and now promotion of actions to focus on equity by tackling social determinants. (Rasanathan, et. al. 2010) This uncertainty continues to be central to WHO debates today.

In summary, in the context of global health policy, community participation has gained both increasing interest and importance in this dialogue. However, universal acceptance of these views presents important challenges in translating the rhetoric of support for community participation into the reality of improved health outcomes. Experience suggests that the search for this causal link is the “holy grail” for health policy makers. In the next section, we will identify 5 critical assumptions about community participation that have shaped program implementation and suggest why they cannot be universally applied. Following this, we will present experiences where these assumptions are being revisited and examined. As a result, programs are beginning to create conditions where participation is critical and sustainable for improved

health improvements. We will then discuss the implications of these experiences for developing a framework to assess the value of community participation to influencing health outcomes.

## **Five Critical Assumptions about Community Participation and Health**

### Assumption 1 People want to participate in decisions about their own health care.

Those involved in the creation of PHC argued people did not use or misused health services because the services did not meet their needs. Service utilization had improved in countries where intended beneficiaries had been involved in decisions about the delivery of services. WHO's book that contributed to the framing of Alma Ata, *Health by the People* (Newell, 1975) provided a range of national experiences that attested to this view. This view was also supported by the Chinese experience of using local people to provide basic health care to their communities, a important contribution to the rapid reduction of communicable diseases in that country (China Health Care Study Group 1974).

However, research to support this assumption has put forward the null hypothesis. Investigations in the period following Alma Ata and continuing to the present suggest a different conclusion. Studies by Rifkin (1985) examining participation in Non-governmental Organizations (NGOs) in Hong Kong and rural Philippines and Indonesia and McCoy et.al. (2011) who undertook a systematic review of health facility committee in low and middle income countries concluded community people did not want to be involved in decision making about health care. Basically, they wanted access to care when they were ill. Identifying incentives for community people to provide that care or to be involved in oversight of the delivery of care in their own communities proves to be difficult. Both studies highlight the complexity of involving community people in activities dominated by health professionals. These complexities most often involve dealing with local politics and ultimately power relationships.

Assumption Two: Providing information will change peoples' attitudes and behaviours resulting in improvement of their own health.

In the period following the creation of WHO policy makers believed that poor health in part resulted from bad health behaviours due to lack of information. Health education seemed to be the key. Efforts on providing information and on mobilizing people to act on this information through mass campaigns became popular. Many of these campaigns focused on control of disease led by health professional with no contribution from the intended beneficiaries.(Gonzales 1965) Mobilization efforts expanded in the post Alma Ata period urging "community participation" in immunization uptake and acceptance of family planning. This approach could be characterized as one in which health professionals told local people what to do. Challenges to this view of participation resulted in the Ottawa Declaration in 1986. (WHO, 1986) The Declaration recognized that for sustainable change people needed to engage in critical thinking and gain confidence through making their own decisions on actions and commitment through empowerment (defined as providing opportunities for those without power to gain knowledge, skills and confidence to make choices about their own lives). (Rifkin and Pridmore, 2001) One result of this realization is that in the literature the term "empowerment" has come to replace "participation" drawing attention to the need for active participation and transformation of thinking in order to create sustainable health changes. (de Vos et. al.a, 2009)

The value of recognizing empowerment as key to change helps policy makers and planners have a more comprehensive view of health improvements. It helps them to recognize factors outside health service provision that influence peoples' behaviours. Yet, often they translate this knowledge into seeking interventions that will give predictable health outcomes. As a result, they often ignore or miss the process whereby mental shifts take place (Rifkin, 1996) In addition, often policy documents state as an objective "to empower local people". However it can be argued that power must be taken, not given. The act of gaining power through struggle is often the experience that empowers

people giving them ownership of subsequent decisions and commitment to sustain these changes. (de Vos et.al a 2009)

Assumption Three: Through empowerment people act they way policy makers think they should.

Following the above assumptions planners then assume “empowered” people will make decisions and take action in their own best interest. These actions are those that have direct causal relationship to improve health and are accepted by all. However, in terms of health behaviours that scientific evidence shows to be effective, people provided with information do not automatically follow or change behaviours. There are many reasons. Many cultures do not see health in terms of scientific explanations. Relationships between good health and its causes are rooted in history, experience and in alternative explanations. African cultures show that although health outcomes might be the same, the reasons for these outcomes for local people can just as well be witchcraft as allopathic treatments.

To complicate the situation, many cultures or communities, do not accept scientific reasoning as a valid. Extremes of such views include the promotion of contraception through injections for women in Africa in the 1980s. Many communities viewed this intervention as genocide by Western governments to eradicate Africans. (Pradervand, 1973) Less extreme is the acceptance by Chinese of both allopathic and traditional medicine for improving health although both systems have different explanations for illness. (Chi, 1994) This assumption in the context of community participation has haunted policy makers continually. People’s behaviours are not as predictable as disease patterns or economic models. The search for the major bullet for predicting human actions is as illusive as the eradication of the HIV/AIDS virus.



Assumption Four The term “community participation” need not be clearly defined before interventions are identified and started.

It is assumed that once a needs assessment is made, an intervention to improve health based on community participation can begin. However, often the terms “community” and “participation are not clearly defined.

Epidemiologists define communities by geographic boundaries or by “targets” for interventions. The difficulty is that with this narrow definition there are confounding variables that affect identifying an intervention and predicting its outcomes. Jewkes and Murcott (1996) highlight the need to examine the role of community “non-members”, those within geographic boundaries but not sharing or participating in the program constructed by planners for inclusion in the intervention.

Participation also has various meanings. It can be defined as a means to improved health outcomes or an end in itself. (Morgan, 2001) It also can be defined as active or passive. Or it can be seen on levels as presented by Arnstein (1969) with the visualization of a ladder with giving information on the bottom rung and community control at the top. It also can be visualized as a continuum with an arrow narrow at one end with information sharing and progressing to consultation, collaboration and empowerment represented by the widening of the arrow. (Rifkin and Pridmore, 2001) Without clear boundaries for each of these terms, it is difficult to examine direct or indirect relationships between the intervention and the outcome. Too often superficial assessments about the critical role of participation is identified by the numbers of people who show interest by coming to a meeting rather than those who change behaviours and attitudes, a much longer process.

Assumption Five Health is a human right not a commodity for consumption.

The four assumptions above focus on the provision of health care and services and the role of the community in accepting inventions usually defined by health professionals. However in the last 10 years, as De Vos et. al.b. (2009 p.26) highlight the discussion of health in the human rights perspective

has become prominent. Taking up the concepts of empowerment and equity and applying them to the right to health as defined by the Declaration of Human Rights (Universal Declaration of Human Rights, 1948) a discourse has developed concerning accountability of governments to provide health care that is transparent, accessible and fair. The discourse has been taken up by civil society with an important contribution by the Peoples' Health Movement, a global network focusing on the rights for health care for the poor (Global Health Watch 3, 2011). Civil society organizations have advocated and organized activities to engage community people in demanding their health rights.

The right to health movement is another indication of a shift in the health care paradigm from the dominance of bio-medicine to the social determinants. However, the current global situation overriding concerns about financing health care has tested this assumption. Lister (2005) discusses the broader situation in detail in the global context. In the context of health and community participation Grace (1991 p.329) argues the current health promotion dialogue, despite its commitment to empowerment, in fact, "constructs the individual subject as a "health consumer" in accordance with the model of consumer capitalism." Those who advocate health as a human right are continually challenged by those who focus on allocation of very scarce resources and an economic environment that encourages products over people.

### **Assumptions Redux: Examination and Experiences**

These assumptions have been the basis of many programs where community participation has been introduced with the expectation of improving health outcomes. We have suggested however without investigation into these assumptions the expectation remains unrealized. Some programs have found ways to overcome the barriers which we have described above. Below we describe a few of these experiences with a view to discuss how realistic assessments can be made to understand the link between community participation and better health outcomes.

Concerning the first assumption as to whether people wish to be involved in decisions about and for health care provision experience suggests it is a question of incentives. Community people need to reflect upon what involvement means to their personal lives. CHW programs illustrate this point. Financial incentives are an obvious inducement but not the only inducement. The case of CHWs is an example. In India, where a national CHW program has been running since 2005, a 5 year evaluation found CHWs stated that receiving payment for specific task ranked as one of the top three reasons for their involvement. However, 80% of those interviewed also ranked serving her community as one of the top three reasons. (NHSRC 2011)

Other studies show incentives can come from the support of the government health system for CHW work. (Kahassay, et. al 1998) Personal incentives also can motivate workers because they learn new skills, gain status in the community, get preferential treatment at health centres and have flexible hours and clear roles. (Bhattacharyya et. al. 2001) CHW programs show local people can actively choose to be involved in health care. The challenges however are 1) to examine reasons for reluctance to participate and 2) to create a conducive environment to sustain their participation.

The assumption that giving information to people will enable them to make better health choices can be examined in the creation of health facility committees where local people have some decision about how services are delivered. McCoy et.al.'s (2011) systematic review of the literature on these committees reveals that information alone is insufficient to empower people. In the four case studies where a rigorous assessment to link committee work with improved health outcomes for patients, a major component involved a long training process for selection and functioning of committee members and continual negotiation between government providers and committee members. In Kenya, for example, a non government organization (NGO), the Aga Khan Health Service, trained government staff at selected health centres and facilitated the creation of a legal entity for these committees. In addition it continued to create dialogues between committee member and government officials. It also provided support for health information and financial

accounting systems. The process had a positive influence on health behaviours including increased utilization of services by local people.

The review highlights several key factors necessary to turn information into power. These factors include an enabling environment where government and local organizations work together, outreach to community people especially those who are underprivileged and underserved and joint commitment of health providers and community representatives to work together for the greater good of the intended beneficiaries. Underlying these factors, the review concludes is the need to address local political dynamics. In other words, information to empower must recognize and deal with power as a key element for success.

Life experiences of all of us teach us that people do not always act the way we think they should. A good reason that people don't behave this way lies in the fact we don't know why they behave the way they do. We mostly assume they think and assess situations in the way we would do so. An expanding area of interest to overcome this barrier is the work in the field of community based participatory research. Influenced by the Brazilian educator, Paulo Freire (2006) and Ranjesh Tandon (1981), this avenue of exploration provides a platform for examining, sharing and consensus building among diverse groups of people. In health, it supports an arena for empowerment and shared decision making between health professionals and their intended beneficiaries. Community based participatory research is action research that includes intended beneficiaries in the entire process of defining, investigating, formulating, and evaluating a community intervention. It allows researchers, program providers and community beneficiaries to learn from each other and take joint ownership of the program.

Minkler and Wallerstein have edited a revised edition on experiences in the United States focusing on local community initiatives. (Minkler and Wallerstein, 2008) Academic programs in America also have taken up this approach. R. Lichenstein (2011) from the School of Public Health at the University of Michigan describes how the program in which he is involved

connects students and poor communities linking the university, the government and local people to provide appropriate care. The program strengthens partnerships among all involved allowing academics to publish and community people to define and discover improved ways of dealing with their health problems.

In other contexts, particularly in low and middle income countries, participatory approaches have been used to improve performance of health staff through participatory approaches. A recently published study about CHWs in Brazil provides evidence that using an approach that combined indigenous knowledge with technical information through experiential learning for CHW training has improved patient outcomes.

CHWs' expertise develops through a cyclical process of experiential learning and teaching involving indigenous knowledge and technical training. Their expertise is refined by consistent contact with patients whose social and health realities mirror those of CHWs. CHWs' expertise can be therefore used to inform the training and subsequent services of professional care providers, such as physicians and nurses. (Pinto, de Silva, Soriano, 2012)

The assumption concerning definitions of community and participation is critical to the investigation of the link between this concept and evidence concerning proven health outcomes. The literature continually points to the fact that without a clear definition of these terms it is not possible to set and evaluate program objectives. (Preston 2010). Again, recent publications are beginning to tackle this concern by clearly stating how for the purpose of the specific investigation these terms are used. Preston and colleagues have undertaken a literature review of community participation's contribution to rural health outcomes. Based on their earlier work of clarifying conceptual confusion their investigation reviewing 689 studies with 37 of these studies proving robust information disaggregates approaches to community participation. They conclude that evidence to link community participation needs overcome the lack of clarity in the literature by increasing our

understanding through experience and investigation of the meaning of these terms.

Where community participation has been clearly defined and given parameters it is more possible to link concepts with outcomes. The Preston review using the 37 studies identify a link between a defined activity for community participation and an improved or lack of improved health outcome. The authors note that it is but a first step in seeking the link and reflects situational not generalizable conclusions as the studies consider only one situation or case study.

Concerning assumptions about health as human right rather than a consumption product, the views more complicated. One reasons that many of the arguments are ideological. To simplify, the human rights views are based in concerns about social justice; the consumer views are based on production and profit. They are not mutual exclusive but they are views about priorities and allocation of resources. As much of the global health dialogue is about the alleviation of poverty, health as a human right garners support from low and middle income countries and underprivileged people in industrial countries supported by from civil society demanding equity. The advocates of the market economy and a small role for the State support the view that health as a consumer product raises the funds needed to provide improved health care. The question is for whom?

In the dialogue of the importance of community participation to health improvements, those who believe health is a human right mobilize their supporters with demands that governments fulfilled their obligations as signatories to the Declaration of Human Rights. De Vos (2009b) and his colleagues give examples from Philippines, Cuba, Democratic Republic of the Congo and Palestine where human rights activists have mobilized local populations to gain commitment of their governments for health care for the poor. Results have increased access and improved local conditions for people in these areas. It also shows evidence of empowerment of these people through struggles and demands for their own care.

## **The Reality of Rhetoric**

This paper has identified 5 key assumptions that have shaped the dialogue in global health policy concerning the importance of community participation for improved health outcomes. It has not investigated the social constructs that underpin these assumptions. A recent article by Marent and his colleagues, (Marent, Foster and Nowak, 2012) has analysed some of the key conceptual constructs in some detail. Rather this paper has reviewed the consequences of the lack of systematic investigations of the assumptions for policy implementation. A review of the translation of policy to practice suggests that the rhetoric poses difficult challenges for planners and implementers. It also suggests that faced with the reality of this translation there are experiences that give evidence positive outcomes.

In conclusion, two observations may be made about the link between community participation and improved health outcomes. The first is that there is evidence that there is a link. However evaluations which seek to prove a generalizable link so far have failed. These evaluations are based on a framework that assesses scientific interventions with the core values of replicability, reliability and validity. They seek the same gold standard which assesses the value of medical interventions to health improvements. The rigidity of these frameworks does not allow values to be given to variables that are not consistent in all investigations. They are challenged because thus far we do not have a genome collection for all human behaviour.

The second observation which is related is that where there is evidence of achievements they have been identified deductively not inductively. Where intended beneficiaries of programs based on community participation have been involved rather than manipulated in program implementation, changes brought about by the program are consistent and sustainable. What has worked in these cases has been examined and analyzed as an ongoing process to tweak the program and to build partnership and ownership. However, to date, the insights from these experiences only reflect the situations in which they are evolving.

The reality is that we are not always clear about the meaning of the evidence we have. Too often we choose to present what preconceived ideas we have about this link. Recent articles have begun to do systematic investigations to more carefully define our analysis of what we observe and how we interpret these findings. We do need to be open and critical about our evidence, recognize our limitations and search for a range of evaluation tools. Finally, we need to continue a dialogue with those who seek gold standards so together we find ways of validating information that will support our mutual goals of improving health and health care especially for the poor and underserved.



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