Political empowerment of marginalized indigenous communities through the monitoring of public health care services in Guatemala

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Abstract:
Rural indigenous communities in Guatemala are not able to access public health care services on an equal footing with wealthier urban populations. Despite a National Political Constitution, which allows for public participation in health care decisions, indigenous people face barriers to doing so. As result, Guatemala’s indigenous population experiences high avoidable infant, child and maternal mortality and extreme poverty.

Using a rights’ based approach to community monitoring of public health care services, a civil society organization (CEGSS) in partnership with Community Based Organizations (CBOs) have developed an implemented a system to implement citizens’ vigilance of public health care services. The approach includes three main components: a) capacity building process aimed to enhance knowledge and skills of indigenous populations about the legal framework, human rights and public policies and services b) data collection and analysis tools to monitor public services used by the communities themselves and c) strategic advocacy to influence public policy making and services. After 5 years of implementation, communities have managed to influence the improvement of public health services at local level and the allocation of resources. However, the most important achievement has been the connection of highly marginalized communities with public policies and services and the overall Estate in Guatemala. This is resulting in the political empowerment of community leaders that
were alienated from public institutions before. At the same time, public health care services in rural areas are receiving an increased attention and resources from central government due to the communities’ monitoring and demands for improvements. All of this is resulting in an increment in the level of trust and collaboration between public authorities and CBOs. The system is now being expanded to over 35 indigenous municipalities of Guatemala.

1. BACKGROUND

There is something starkly wrong within Guatemalan society: a middle income economy which is among the top five world exporters of sugar (FAO 2003) and coffee (ICO 2010), but in which almost 50% of all children under five years of age are stunted, making Guatemala the fourth country in the world with the highest concentration of chronic malnutrition (UNICEF 2011) which causes serious long term effects on learning, growth and overall opportunities for children.

In addition, malnutrition in indigenous children (70%) is much higher than the national average and twice as high compared to non-indigenous children (INE 2002), showing the high burden of inequities within the indigenous population. Moreover, indigenous women are three times more likely to die in child birth than non-indigenous (MSPAS 2003). Indigenous children are twice as likely to be out of school and therefore receive no education than non-indigenous children (Center for Economic and Social Rights and Instituto Centroamericano de Estudios Fiscales 2009).

The above indicators are the result of complex structural determinants that influence the distribution of power, income, goods and services. The effects of these determinants reach people’s lives, conditions of work, access to school and other essential services, including how services are provided and received. Overall, these determinants shape health care outcomes and consequences both at the individual and population level (CSDH 2008).

In addition to the historical exclusion of poor and indigenous populations from development, the armed conflict from 1960 to 1996, was one of the most vicious and violent in the American continent. Guatemala’s Historical Clarification Commission (CEH in Spanish language) estimated that 200,000 people were executed or “disappeared” and the number of orphans as a result of the armed conflict approached 150,000. The massacres and destruction of villages gave rise to forced displacement of the civilian population and more than 1.5 million people were displaced [8]. Although the political violence affected more than one third of the population, the largest burden of violation fell on indigenous population—more than 80% of all crimes verified by the CEH were on indigenous citizens (Comisión para el Esclarecimiento Histórico 1999).

While it is clear that indigenous population in the country (about 40% of the total) are lacking access to essential health care services, one cannot ignore the oppressive power relations that has historically run through Guatemalan society and which has put indigenous people at disadvantage. This oppressive power relations also have an
effect on both peoples access to needed services and health outcomes. Because of that, the Commission on Social Determinants, among its three main recommendations, included tackling the inequitable distribution of power, money, and resources (CSDH 2008).

Implementing the above recommendation imposes enormous challenges. Unequal distribution of power and resources occur at the global level and between countries. However, it also occurs within countries. Tackling the distribution of power entails the asymmetries between the state and citizens, particularly in post-conflict and fragile states (Flores 2011).

In the year 2007, a civil society coalition (community based organizations, local health care workers and researchers), led by Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud (CEGSS), took up the challenge of addressing inequities in health faced by rural indigenous population through confronting and transforming inequities in power relations. Based on a human rights framework, this coalition designed and implemented a participatory-action research approach to challenge power relations at 6 municipalities with a majority of indigenous population in the western highlands of Guatemala. The main idea behind this approach is that empowered rural citizens can affect the power balance in public decision-making and lead to pro-equity public policy and resource allocation.

This article summarizes the advances, challenges and lessons learned of the initiative described above. This initiative is still on-going and evolving.

2. CONTEXT

The initial section described briefly that Guatemala is a society embedded in inequity and social exclusion. However, since the return to democratically elected governments (1986) and the signing of the peace accords (1996), there have been important social reforms and the passing of progressive laws that have strengthened the legal frameworks. Some of these advances and the challenges they face in their implementation are described below.

The country has implemented some progressive laws that recognize the right to health and that promote the participation of citizens in the development, implementation and evaluation of public policy. Although this legal framework is a major step forward, the effective participation of citizens, particularly those affected by inequity and social exclusion, is very limited. Barriers include distance, transport costs and travel time, having less formal education and speaking languages other than the official language of mainstream business (Spanish). These barriers prevent indigenous citizens from actively engaging in the deliberation of public policy and influencing the allocation of public funding towards services that can benefit them. These barriers affect the possibilities of rural indigenous citizens to actively engage in the deliberation of public policies and to influence the allocation of public funding towards services that can
benefit them and at the same time reducing the large inequity gap between rural versus urban and indigenous versus non-indigenous populations. Overall the above barriers reflect “asymmetrical power” conditions within Guatemalan society as shown by recent research (Flores and Gómez 2010).

3. PLANNING THE INTERVENTION

As stated earlier, CEGSS’ has led the coalition and the intervention. Since the beginning, there was an active effort to pursue two very important conceptual and methodological tasks: a) understand power and power relations and b) citizens affected by inequity should be involved through the project. These two tasks are explained below.

3.1. Understanding power and power relations

Power lies at the center of social relationships. However, there is no a single concept that would capture its meaning and would have agreement among theorist and practitioners. Instead of attempting to present a definition of power, it is more useful to understand its attributes and why it is important for development work. For instance, power has the ability to produce changes in society. Those changes, nonetheless, can be either the product of conflict or consensus according to Haugaard, M (2002).

From the perspective of conflict, power is a determinist force “possessed” by an actor, and it can be taken away by another through struggles that may even be revolutionary processes as mentioned in Poulantzas (1968). Actors can legitimize their power and dominance through social structures (religion, formal education, laws, economic system, and stratifying social groups by caste, race and others) that reproduce their interests and create relations of dependence as described in recent research (Clegg S, Courpasson D, Phillips N, 2007)

From another perspective, we can also create and multiply power through consensus. Power is based on the human capacity to act together. Therefore, power does not belong to only one actor but rather to a social group and is generated through the creation of agency, as noted in Arendt, H (1970). The idea of power through consensus and agency should not be confused with naïve perceptions about social relations. For instance, Flores et al., (2009) argue that “the inclusion of traditionally excluded groups in decision-making processes does not create agency unless there are actions or policies that improve the material conditions of this population. Likewise, assigning resources to improve the status quo can generate opposition and conflict with those actors who benefit from the existing power structure, which also interferes with creation of agency” (page 39).

A third perspective looks at power as a dynamic force and a capacity in latency (Morriss P, 2002). Power is expressed as “influence” in decision-making. From this view, there are no powerless individuals but people who are yet to become conscious about and activate their latent power to exercise influence over issues of their concern. The above
view of power as a “latent” force that becomes activated or released is useful to explain recent social changes in several South American countries. The “piqueteros” movement in Argentina (Benclowicz J., 2006), worker’s unions and peasants in Bolivia (Regalsky P., 2006), and the indigenous movements in Ecuador (Pachano S., 2005), are all examples of how traditionally social excluded groups became “conscious” of their latent power, and activated it to generate a shift of power resulting in a change of governments and social policies.

The recognition of social, economic and cultural rights by many nations, provides a vehicle to address the redistribution of power. Socially excluded citizens must become aware of that power and activate it through applying the legal framework. Different strategies and actions (i.e. capacity building, advocacy, solidarity) must be implemented to activate the power of socially excluded citizens.

3.2 Involving citizens affected by inequity through participatory-action research:

In health systems research, there is an emphasis on evidence and research produced through quantitative approaches, such as large household surveys, modelling studies, econometrics etc., that are mostly undertaken by academic experts. There is little reference to evidence and knowledge produced through other methodological approaches such as participatory-action research, in which citizens, particularly those affected by inequities, actively participate in data gathering, analysis and in debating policy reforms and monitoring their implementation (Fals-Borda O., Rahman M., 1991).

Participatory-action research (PAR) draws on the paradigms of critical theory and constructivism and may use a range of qualitative and quantitative methods (Baum F., MacDougall C., Smith D., 2006). PAR transforms the role of those usually participating as the subjects of research, to involve them instead as active researchers and agents of change (Minkler M., Wallerstein N., 2008). PAR has been used to study a range of health systems issues—from action on social determinants of health, through community health outreach, to improving quality of services (Minkler M., Wallerstein N., 2008) PAR methods systematize local experience and organize shared collective analysis on relationships and causes of problems. PAR links such analysis to reflection and action, organizing shared experience and perception to generate new learning and knowledge. (Loewenson, R. et. al. 2011).

Within CEGSS’ approach, there is a commitment to collaboratively work with poor, rural indigenous organizations in their efforts to influence public policy and achieve a more pro-equity resource allocation at the municipal level. By applying tools and techniques from participatory action research and the direct involvement of “aggrieved” citizens, CEGSS seek to strengthen the “citizenship” of rural indigenous population.

The two conceptual and methodological themes described above crosscut the four-implementation phases of the CEGSS’ approach. Each of the four phases is described below.
4. IMPLEMENTING PROCESS

Following the two conceptual and methodological themes described above, CEGSS’s approach is implemented in 4 phases. Each phase is described below

4.1 Phase 1: Initial appraisal study:

The initial appraisal involves a rapid analysis of local conditions in relation to access to healthcare services, availability of essential resources at healthcare facilities, power relations (trusts) and key characteristics of democratic governance (accountability, transparency and social participation). The appraisal also applies rapid ethnographic techniques (social mapping, document analysis, participant observation and in-depth interviews) to analyze and understand power relations. As part of the Participatory-Action Research (PAR) approach, CBOs are involved in the initial appraisal study. CEGSS discusses and agrees with them the particularities of the study and then develop/adapt jointly the data collection tools, training to use the tools and support for data analysis. This initial appraisal is very important to define the situation at the beginning of the intervention, which allows community organizations to identify whether their efforts is leading to changes (increased availability of essential medicines and supplies, better treatment to families while seeking healthcare, improved communication between families and healthcare providers). During CEGSS’ previous projects, it has been demonstrated that monitoring changes occurring at the process and output level, is very important to maintain citizens’ motivation and confidence in their involvement. This initial phase lasts between 3 and 5 months.

4.2 Phase 2: Capacity building process:

Based on the findings of the initial appraisal study, a capacity building process was designed and implemented with the participation community representatives and some local authorities. These workshops, based on popular education and adult learning techniques, developed skills and knowledge around the following themes:

- Legal framework for health and social participation in Guatemala.
- Public polices and the role and responsibilities of different actors.
- Participatory planning and monitoring.
- Implementing participatory monitoring for accountability.
- Strategies and activities to demand accountability of authorities and advocacy.

The above capacity building was organized around 7 one-day workshops and study guides for participants to study at home. However, there may be up to two additional
workshops based on the interest of CBOs that are local partners (i.e. some are interested in expanding the participatory planning and monitoring training and other training on strategic advocacy). This second phase lasts between 7 and 10 months.

4.3 Phase 3: Participatory monitoring of public health policies and healthcare services

This stage involved designing, field testing and implementing a participatory system to monitor whether public polices and resources at the municipal level were addressing and resolving the access to health care problems.

For monitoring policies and resources, two instruments were developed: a) health care facility surveys to assess availability of essential drugs, medical equipment/supplies and availability of human resources; and b) an interview guide for families who had faced a health care problem, had gone to a public health care facility but did not receive adequate care. The purpose of adding family interviews was to demonstrate that the inability of public health care facilities to solve the basic health care needs of families has a negative impact on their survival. They had to use scarce resources to pay for medicines, transport to a central hospital, and also endure working days lost to illness. Community leaders were trained to apply the instruments and to carry-out the analysis of collected data.

The figure 1 summarizes the design of the monitoring system. The central problem to address is the complaint by rural citizens that they are not receiving the health care services needed from public health facilities (box 1 in the graph).

The monitoring system has a steering commission (box 2 in the graph) with representatives from health authorities, municipal authorities and CBOs called COCODE- which is an Spanish acronym for Community Development Council.

Representatives from COCODE carry-out two main tasks: a) to evaluate and monitor the availability of resources and resolution capacity at public health care facilities (Box 3 in the graph) and b) to collect information and monitor families’ experience while seeking health care at public healthcare facilities (Box 4 in the graph). Each of these two tasks has their own data collection tools and they are listed below box 3 and 4. It is important to note that the standards for availability of drugs, medical equipment and human resources at healthcare facilities, are all based on the national standards set by the Ministry of Health. The monitoring evaluates whether surveyed healthcare facilities are complying with availability of drugs, medical equipment and health personnel as stated in the national norms and protocols. Initially, the survey included all the essential drugs and medical supplies from national norms, which were between 75 and more than one hundred items. Although comprehensive, applying these tools was lengthy and took a good deal of time from community members who are volunteers. In the first quarter of the year 2011, CEGSS and CBOs developed and field tested new data collection tools using tracer drugs and medical equipment. These new tools greatly reduce the time that community volunteers need to allocate to carry-out the monitoring process.
Collected information is fed into a simple database (Box 5 in the graph). The analysis is carried out by community boards with the technical assistance of CEGSS. A report is produced and findings presented during the meetings of the Municipal Council for Development (COMUDE). From these meetings, an action plan is drafted with decisions aimed at correcting problems and allocating resources towards needed services and communities (Box 6 in the graph). The next step is to monitor the decision-making process, and whether targets are being achieved (Box 7 in the graph). The monitoring of decision-making has an emphasis on democratic governance variables (social participation, transparency and accountability). Previous research implemented by CEGSS found that decisions at the COMUDE occur under very asymmetrical conditions (usually community representatives from further areas are at disadvantage). The system therefore includes tools to monitor whether decisions are benefiting communities facing larger shortage of resources and also whether transparency and accountability is being strengthened throughout this process. Those specific tools are listed under box 7 in the graph.

The analysis of findings on the implementation of action plan, decision-making process and whether targets are being achieved is fed back into the central problem (box 1) to assess whether the collective action of social actors (policy makers, health authorities and community based organization) is improving rural citizens’ access to healthcare and the accountability of authorities at the municipal level. The results of this assessment inform a new cycle of data collection, analysis, adjustments to action plans and monitoring implementation and decision-making which in turns feed information to initiate the next cycle. Each CBO decides the frequency of data collection rounds, but in the 6 municipalities already implementing the system, data collection occurs every 6 months.
4.4 Phase 4: Advocacy actions:

The findings of the monitoring process are the main input to plan and agree on the strategies and actions to demand accountability of public authorities and changes related to allocation of resources to improve availability of essential drugs, medical supplies and personnel at public healthcare facilities. Actions to be implemented include the analysis of political forces and seeking alliance among political actors (members of parliament and others) and use of mass media (newspapers, radio and others). In each
of the 6 municipalities, there has been monthly meetings to discuss and agree on advocacy actions and review the outcomes of implementing such activities. In the year 2010, CEGSS in collaboration with CBOs produced three educational newsletter and three educational radio programs. These advocacy actions generated a good deal of interest among authorities and the general public. These tools are available at CEGSS website (www.cegss.org.gt).

4.5 Roles of different partners

The specific key roles for each of the involved partners are described in the table 1.

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<th>PARTNERS</th>
<th>KEY ROLES</th>
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| Representatives from community based organizations (CBOs) | - Providing inputs to the analytical frameworks and data collection tools to be developed by project team.  
- Participating in data collection and analysis for the baseline and end of the project studies.  
- Participating in capacity building workshops and all other meetings and activities related to project’s intervention phase.  
- Lead the participatory monitoring process (data collection, analysis and reporting) at municipal level  
- Leading monthly advocacy meeting and implementing advocacy actions.  
- Provide inputs to produce educational newsletter and audio recordings for advocacy.  
- Providing inputs and suggestions to improve project’s work-plans |
| Representatives from municipal government           | - Providing physical space to carry-out the capacity building workshops  
- Providing information during baseline and end of the project studies.  
- Participating during individual and group interviews to elicit data related to project objectives.  
- Meeting-up with CBOs to discuss and agree on actions to improve access to health care and resource allocation |
| Representatives from municipal health authorities    | - Providing information during baseline and end of the project studies.  
- Participating during individual and group interviews to elicit data related to project objectives.  
- Meeting-up with CBOs to discuss and agree on actions to improve access to health care and resource allocation |
| Project team (CEGSS)                                | - Overall project design and technical assistance for data collection tools and analysis (with inputs from the other stakeholders described above).  
- Developing, printing and distributing all educational material required for the capacity building process. |
- Financing food, transport and accommodation during capacity building workshops.
- Providing technical assistance to CBOs during development and implementation of strategic advocacy plans.
- Taking into account the inputs from CBOs, producing educational newsletters and audio recordings for advocacy.
- Responsible for financial administration of project resources and writing-up final project report to donors.

Table 1. Partners and their roles in the implementation of project. Source: Project documentation CEGSS 2011.

5. EVALUATION OF RESULTS

In the year 2010, an external formative evaluation\(^1\) was carried-out. This was a rapid assessment (Pierre de Paepe, 2010) that included the following aspects:

Documentary review:
- Original project proposal.
- Technical documents developed by the project (conceptual framework)
- Technical reports 5 (August 2006 - January 2009) and 6 (February - October 2009)
- Financial reports.
- Databases and formats developed by the project (mainly the monitoring tools)
- Academic articles published by the project team and other articles submitted or in draft format.
- Training material developed by the project.

Semi-structured interviews:
During the field visit, a semi-structured questionnaire was applied to a series of stakeholders in the project as follows: 8 group interviews to community representatives, 2 interviews to municipal staff, 4 interviews to Ministry or Health staff; 2 interviews to other civil society organizations that collaborate with the project.

5.1 Main findings:

The main findings of the formative evaluation were as follows (Pierre de Paepe, 2010):
- The project has succeeded to install a feeling of empowerment in community members, enabling them to reduce somewhat the power and information asymmetry. This is probably the most important result of the project as far as its sustainability is

\(^1\)Formative evaluation is undertaken during the design and pre-testing of programs to guide the design process. Emphasizes questions related to how the program is operating. Used to assist planners, managers and staff to develop a new program or improve an on-going program. Source: Center for Disease Control and Prevention-CDC. Glossary of Terms in Evaluation of Programs.
concerned. One president of a health commission called it an “awakening in health”, meaning the community now woke up to understand their rights in health and they were able and willing to fight for them.

- Development of a conceptual framework of governance in health: governance as a cycle with inputs, processes, outputs. The concept of asymmetrical power was developed and presented nationally and internationally. The project team developed data collection and analytical tools to analyze asymmetries among COMUDES (Municipal Council for Development) participants in three main areas: educational level, geographical and financial barriers to attend meetings and confidence of participants on skills and knowledge to influence decisions.

- Project staff considers that there was less refusal of collaboration with the project than expected from municipalities and health districts, once partners got to know each other better and authorities understood it was also their long-term benefit to have better functioning health services.

- Health personnel of lower status (technicians, not doctors or nurses) increasingly integrate health commissions; this is a positive development, though of course they are torn between their solidarity with communities and the constraints of belonging to the MoH.

- Concrete results of health commissions lobbying already exist: more personnel in some health services, breakup of contracts with NGO providers of services due to pressure from health commissions, sanctions for doctors offering bad human treatment of indigenous people and better human treatment by other personnel, better hours for provision of services, services during the weekend, awareness among health staff that problems exist and things can and should be improved.

- There is an active presence of many women in health commissions, which is contributing to empowering female gender.

5.2 Specifics findings related to community empowerment and a change in power relations:

The group interviews with community representatives and review of project documents revealed that as a result of the participatory monitoring process and advocacy, community leaders presented the analysis to local health and municipal government authorities. They accompanied the presentation with specific demands to improve the situation. Although the process is still in its early stages, there have already been achievements. Municipal governments have increased their funding to buy petrol for the local ambulance during emergency transport (families were paying before). Two sub-contracted providers for immunization and other basic health services had their contracts terminated due to corruption (revealed by the monitoring work of communities). The working hours of health facilities have been extended, and
complaints by indigenous families that they had received disrespectful treatment by medical doctors have been taken seriously.

The above achievements have resulted in a tremendous boost in the self-confidence and motivation of community leaders. “I feel this is an awakening for all of us; we know now that it is possible to demand our right to health and we have seen that change is possible,” One leader stated, during the group interview.

Another female community leader said: “Through the training and monitoring system we are now capable of discussing with the doctors and municipal authorities the problems with medicines and personnel in the health centre and health posts. Before that, we had to accept that services were almost never there and we thought nothing could be done about it.”

5.3 New evaluations:

It is clear that there is a strong potential in the approach being implemented by CEGSS. However, there are important challenges that need to be addressed. At the moment, there is continued interest in the approach by other civil society organizations and donors, hence an expansion of the intervention to new municipalities is now underway. Taking into account the findings and recommendations of the formative evaluation, and also the current international interest on rigorous impact evaluation of community empowerment initiatives (Rosemary McGee & John Gaventa, 2010; Wallerstein N 2006; T/A Initiative 2014), CEGSS is at the moment implementing a randomized control trial to assess the impact of its approach to social accountability of public health care services and policies.

6. LESSONS LEARNED AND SUSTAINABILITY

6.1 Lessons on researching and tackling inequities of power:

Reflecting on the process carried-out by the project, team members have been able to identify three main lessons that may be useful for others aiming to researching and tackling inequities of power.

First, participatory action-research is not only a research approach but also an approach that can be used in adult education and the generation of political action. This project embraced participatory action-research because in addition to being an effective method of collectively producing knowledge, it provides the tools to question power at all levels. So far, our experience in applying participatory action-research to health systems research and actions has shown that: 1) the participation of ordinary citizens in the production of evidence and knowledge provides a strong legitimacy to research findings; 2) it is an empowering process for citizens; and 3) it may be an entry point that generates actions on other social determinants of health. Participatory action-research
is also relevant to multidisciplinary teams, for example, this project team includes anthropologists, sociologists, and a political scientist, in addition to public health and health policy experts.

Second, it is important to facilitate an alliance among all individuals and groups that experience different levels of exclusion. Rural indigenous citizens have historically been excluded from development, whereas front-line health care workers, working within a hierarchical and professionally controlled organization, are also often excluded. The empowerment of front-line health care workers is crucial. They should form an alliance with community-based organizations seeking to influence pro-equity resource allocation.

Third, it is important to be aware of and understand the health politics and complex power relations occurring at central, regional and local government level. Demanding transparency and accountability from all the actors with vested interests in policy-making is a way of tackling the inequities of power at all levels.

6.2 Sustainability

Our participatory-action research approach to empowerment of rural indigenous citizens has attracted the interest and support of other donors. At this moment, there is secured support until 2015. In addition to international funding, our approach is also generating support from national NGOs and some government agencies that have as mandate, the promotion of citizen participation in public policy. Up to now, our approach has demonstrated to require minimal external financial resources since it mainly relies on the facilitation of capacity building processes. Most of the civil society coalitions that are engaged with the process are already present in these municipalities, hence reducing greatly the need for external funding. In addition, our approach does not envisage sustainability in the traditional way in which activities are expected to continue once external funding is ceased. Rather, sustainability relates to maintaining and increasing the level of resources that rural citizens have achieved through their demands and expanding the social mobilization to act upon other social determinants of health (such as education, food security and others). In other words, our approach is an entry door or catalyst for rural citizens’ struggles to gaining access to other essential livelihood resources.

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