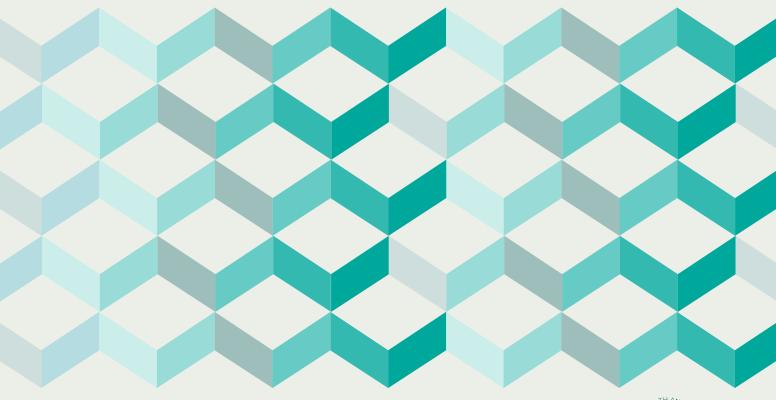


# Empowering Marginalized Indigenous Communities through the Monitoring of Public Health Care Services

in Guatemala

Walter Flores, Lorena Ruano











Publisher: Centre for Health and Social Justice (CHSJ), COPASAH Global Secretariat

Design and Print: Aspire Design

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## Empowering Marginalized Indigenous Communities through the Monitoring of Public Health Care Services in Guatemala

This case study is part of a series of papers commissioned by the Community of Practitioners on Accountability and Social Action in Health (COPASAH).

#### Acknowledgements

To the Open Society Foundations for their overall support to COPASAH.

**Cite as:** Flores, Walter and Ruano, Lorena (2014). Empowering Marginalized Indigenous Communities through the Monitoring of Public Health Care Services in Guatemala. New Delhi: COPASAH, CEGSS and CHSJ

## **Executive Summary**

Guatemala's history of discrimination, exploitation and war has had a profound impact on the health system today. Many of the health inequalities that can currently be found have a direct relationship with Guatemala's larger social issues. The country's health inequities are intrinsically linked to inequities of power. As a result, rural and indigenous populations find themselves at great disadvantage when it comes to obtaining quality health care. In order to understand and deal with these social issues, we developed a participatory action-research project. Through the use of a rights-based approach, our goal was to contribute to the empowerment of rural and indigenous citizens and help to get them involved in the monitoring of public policies, of health care services and in the process of resource allocation. Over the course of four years, we analyzed and studied the source of Guatemala's inequities in health, designed and implemented an intervention program that worked with local leaders and that presented community monitoring for accountability as an opportunity for change. After that time, we evaluated our work alongside our community partners.

The result of this four-year process has helped us identify strategies that include systematic work at the community and health district level. In this report, we present the experience of our program for the period 2008-2011 and reflect on our strategies and decisions, accomplishments and the challenges faced. The document further discusses how the project is changing the existing power relationships and presents a possible way forward through the process of reflecting on the lessons we learned in the with an aim to highlight the sustainability of similar projects and the outcomes that can be expected.



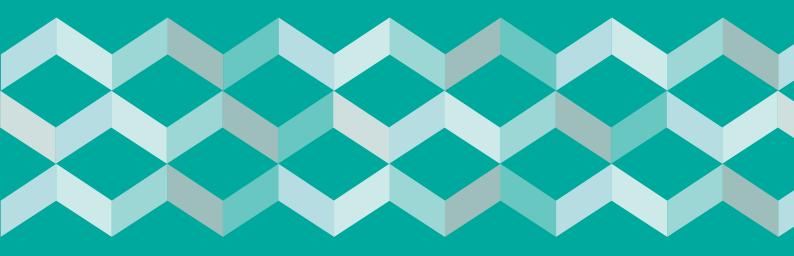
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## Chapter 1

# CHANGING POWER RELATIONSHIP THROUGH COMMUNITY MONITORING



If we look at power from a 'conflict' perspective, we find that many social processes are determined by how stakeholders are able to replace social structures like religion, education, formal and informal rules, the economic system and even social class.

## Introduction

Although it is clear that power can be found within all social relations, knowing exactly what power is or how to define it is not as clear. There is no single concept that can grasp such a complex meaning and that will satisfy both academics and practitioners. This is why in our report we will try to focus more on understanding how important the dimension of power is within development work and then start to explain what power is and how it works from there (13).

We begin by acknowledging that power has the ability to produce changes in society, just as much as these changes can be the result of conflict between stakeholders or, on the contrary, of consensus. If we look at power from a 'conflict' perspective, we find that many social processes are determined by how stakeholders are able to manage social structures like religion, education, formal and informal rules, the economic system and even social class. These different structures give stakeholders legitimacy and help to create an environment that is more prone to staying the same and perpetuating the status quo than to promoting change. This is because powerful stakeholders can use these social structures to mould society into what they need it to be, without necessarily considering the position of less powerful stakeholders (13-15).

The perspective of power that looks at it as the result of the building of consensus between stakeholders takes a different approach: power is the result of the human capacity to act and work together. This means that power does not belong to one stakeholder but to many, and that by creating more consensuses and including more stakeholders in a social process, the process itself becomes more powerful. However, this is easier said than done. It has been proven in other contexts than simply including new stakeholders into a process does not automatically generate agency and power for these new participants. For that to happen it is necessary to award adequate power resources or to redistribute them among all the stakeholders so that there is a balance that will allow for equal and fair participation in consensus-building (16,17).

Power can be expressed in the capacity that a stakeholder has for dynamic action or for latency. Stakeholders are powerful even when they are not mobilizing their resources. This means that even when they are not acting, they can still influence decision-making processes simply by being a participant. Even stakeholders that have not acted before can use their latent power or turn it into dynamic action simply by organization and acting. Examples of this are the cases of social movements in Latin America, where groups of traditionally excluded stakeholders were able to influence and generate shifts of power (18-21).

While the examples of the Argentinian *piqueteros* or the indigenous people's movements in Ecuador show the power that organized groups of disenfranchised citizens can have, it is not necessary to wait for such dramatic social conflict to

If we look at power from a 'conflict' perspective, we find that many social processes are determined by how stakeholders are able to manage social structures like religion, education, formal and informal rules, the economic system and even social class.

...cases of social movements in Latin America, where groups of traditionally excluded stakeholders were able to influence and generate shifts of power... bring about social change. Participatory action research (PAR) is a tool that researchers and practitioners can use to involve excluded populations in the process of recognizing, analyzing and changing social conditions through the use of evidence-based research practices. When it comes to health system research, PAR can be a useful tool that can act as a bridge between the health system and the population it is meant to care for by making the health system more responsive, aware and better able to provide healthcare (22,23).

Participatory action research draws on the paradigms of critical theory and constructivism, and can use quantitative, qualitative or mixed approaches and helps to transform the role of people from 'research subjects' into active agents of change. PAR is used to study a wide range of health system issues that go from studying the social determinants of health to community outreach, and improving health services. This is achieved by using methods that systematize local experiences and that allow for collective analysis that lead to reflection and action, and ultimately, to social change. (23-26). This report summarizes the advances, the challenges and the lessons we learned as a team of researchers working in rural Guatemala while trying to implement a PAR project to improve the quality of care (availability of resources, access, reducing maltreatment) that is provided to the excluded rural indigenous population.

## The Guatemalan Experience

#### GUATEMALA AND ITS INEQUALITIES IN HEALTH

Guatemala is a Latin American country, which like Peru, Ecuador and Bolivia, characterizes itself for having large indigenous population belonging to many different ethnicities. While it is a middle-income country, the wealth that exists within it is not equally distributed: Guatemala is among the world's top five producers of coffee, but it is also among the top four countries when it comes to chronic child malnourishment. This means that though there is enough wealth produced in the country and it has fertile lands capable of yielding food crops for its 14 million inhabitants, but, almost 50% of Guatemalans are poor and one in every two children suffers from chronic malnutrition and stunted growth (1-3).

These numbers become even more startling when we break them down by ethnicity. While indigenous people make up only about 40% of the population, the malnourishment rate in indigenous children is 70%, a figure that is higher than the national average and almost twice as high as the malnourishment rate is for non-indigenous children. Schooling indicators show a similar trend, and indigenous children are also twice as more likely to be out of school than their non-indigenous counterparts. Women fare scarcely better: an indigenous woman is three times more likely to die from complications arising from child birth. (4-6)

There are no simple explanations for the Guatemalan case. These indicators are the result of complex structural determinants that have influenced the distribution of power, wealth, goods and services for several decades. As a result of these determinants,

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people's lives, work conditions, life chances and access to health and education are severely diminished (7). Why is this a reality for so many Guatemalans? In addition to the historical exclusion of poor and indigenous populations, the country underwent one of the most violent and cruel armed conflicts in the whole region. This internal war, which lasted from 1966 to 1996, left an estimated 200,000 victims of execution or forced disappearances. An additional 150,000 victims became orphans as a result. In total, there were about 1.5 million victims that were murdered, raped, orphaned or geographically displaced. While this number of victims represents about one third of the total population, the burden of this war mainly fell on the indigenous population, who were the victims of up to 80% of the crimes (8-9).

The indigenous population in the country lacks access to essential health care services, and is in a position of vulnerability due to the historical and social determinants discussed earlier. One way to deal with these determinants is to tackle the inequitable distribution of power, money and resources (10). While this is not an easy task, a first step is to work with civil society coalitions and involve them in PAR that can help to bring these systematic exclusions out in the open through evidence that can help stakeholders to secure spaces at participatory and decision-making spaces.

#### DESIGNING AND PLANNING OUR INTERVENTION

The PAR approach was conducted in close collaboration and partnership with community based organizations. We discussed and agreed on every aspect of our study and worked together to develop data collection methods. We present the different processes in implementing the project using the PRA tool, discussing our experiences and lessons learnt

To begin our intervention we wanted to quickly and adequately assess two things:

- First, the conditions of access to health care services and the availability of
  essential resources at health facilities. This involved gathering data from the
  health system in a way that would allow us to compare and track whether there
  are changes in the availability of essential drugs and other medical supplies, and
  identifying the key problems in terms of resource availability for our project.
- Second, gather data for our assessment. The data to ascertain the trust levels of the community, so that they themselves feel the need to access health services and the key characteristics of the local democratic governance processes where we would be working. To do this, we measured power relationships as well as the way accountability, transparency and social participation occurred. We did this by relying on rapid ethnographic techniques such as social mapping, document analysis, in-depth interviews and participation observation. The product of this process was a first understanding of how power relations worked in the municipalities that were part of our project. This initial appraisal was an important tool to define the situation at the beginning of the intervention. It gave community leaders and organizations a way to identify and track their

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processes and the changes regarding the increased availability of essential medicines and supplies, better treatment to families, and improved communication between the community and the health care providers. This part took about five months and was fed by our previous experiences that showed that monitoring changes that occur at the output level is important to maintain the motivation and confidence of our community partners.

Once this initial appraisal was done and the data was analyzed, we took our findings and used them as the foundation for a capacity building process aimed at involving communities and local health authorities. We did this through workshops that were based on popular education techniques and adult learning. Through these spaces, we developed skills and knowledge around a few key themes:

- The Guatemalan legal framework for health and social participation in Guatemala.
- Public policies and the role and responsibilities of different stakeholders in the process.
- Participatory planning and monitoring.
- Implementation of participatory monitoring for accountability.
- Strategies and activities related to demanding accountability from the authorities and strategies for advocacy.

We were able to do this by having seven workshops that lasted no more than one day each and by supplying all the participants with study guides that they could work with at home. In case our community partners were interested in more information, we also offered the option to have two more workshops. Our partners who took the offer for additional training chose to work with participatory planning and monitoring and on strategic advocacy. This second phase lasted between seven and ten months, depending on the municipality. One day workshops were conducted based on the suggestions from communities.

#### THE PROCESS OF MONITORING

The third phase (implementation) of our intervention was the actual implementation of the project, after we had worked on capacity building with our community partners. In this stage, we did field testing and implementation of the participatory system of monitoring that would help to keep track of the policies and resources that were used at the municipal level to address and solve the problems in accessing health care.

We developed two tools to help us with the process of monitoring policies and resources. The first tool was a health care facility survey that would help us track the availability of essential drugs, medical equipment and supplies, as well as the availability of medical resources. The second tool was an interview guide that would help us conduct interviews with families who had faced a health care problem and did not receive adequate care. This interview guide provided information on the inability of the public health care facilities to solve basic needs of the people, having a negative impact on the family's capacity for survival. The interview guides covered the topics of payment

for drugs, transport and loss of work. Community leaders received training to conduct the interviews and analyze the data on receiving the data.

The Figure 1: Community Monitoring System implemented during the period 2008-2011, (See Box 1, Central Issue) shows the process of designing our monitoring system. It shows that the central problem when addressing complaints from these rural families was that they do not receive the care they need from the facilities that are there to provide them with it. Box 2 (Actors in the monitoring process) shows a steering commission with representatives from the health system, the municipality and community organizations, which in Guatemala are called community-level social development councils or COCODES in Spanish.

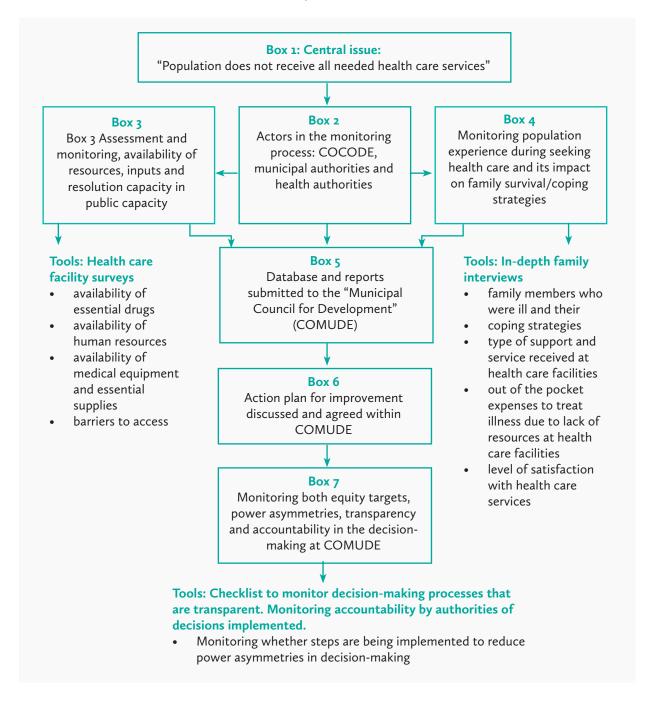
Representatives from the COCODES councils carry out two main tasks in this process. The first is to evaluate and monitor the availability of resources and the resolution capacity that exists in public health facilities. This is shown in Box 3 (Assessment and monitoring) of the same graph as before. The second task involves collecting information and monitoring the experiences of families who were seeking health care and public health facilities. This is shown in Box 4 (Monitoring population experience during healthcare, Monitoring Community Experience.) In order to make sure we were measuring the existence and availability of drugs and medical equipment with national standards, we compared the data with the MoH standards. This helped us understand if the facilities were in compliance with national norms and protocols. Initially, we surveyed the essential drugs and medical supplies as per the national norms. However, this made for an extensive list that consumed much time from the volunteers gathering the data. Due to the time constraints that exist among community members, we worked with the COCODES to develop and test new data collection tools with only tracer drugs and medical equipment. These new tools developed in the first quarter of 2001, greatly reduced the time required for data collection and allowed for the additional time to carry out the monitoring process.

The information we collected from the fieldwork was fed into a simple database that is shown in Box 5 (Database and reports). Community members carried out the analysis of the data, but we still worked closely with them to provide any technical assistance that would be needed. The result of this process was a report that presents the findings and that was presented in meetings for the municipal-level social development council known as COMUDE in Guatemala. The report worked as a starting point for action, and during these COMUDE meetings, decisions aimed at improving the identified problematic situations were decided. This is shown in Box 6 (Action plan for improvements) of the figure.

The process of monitoring decision-making processes was carried out with close collaboration with community partners. Our emphasis was on democratic governance variables such as social participation, transparency and accountability. In previous research projects we had worked on, we found that decisions made at municipal-level commissions tended to be asymmetrical and tended to put representatives from communities in disadvantaged positions for negotiations.

Because of this, we included tools that would help us to keep track of whether the decisions that were made benefited communities. These tools are presented in Box 7 (Monitoring both equity targets).

FIGURE1. COMMUNITY MONITORING SYSTEM IMPLEMENTED DURING THE PERIOD 2008-2011. SOURCE: CEGSS PROJECT DOCUMENTATION



In summary, the analysis of the findings were presented and converted into an action plan. Once this was implemented, we analyzed the implementation, decision-making process and started setting targets to overcome the central problem identified originally. This helped us assess the actions of stakeholders such as, policy makers, health authorities and community organizations and improve access to health care,

building accountability of health systems and the functioning of the authorities at the municipal level. The results of the assessment were information pointers to the monitoring cycle of the process. The monitoring cycle was conducted every six months, in order to have ample time to develop and implement a plan, and to evaluate its outcomes.

The final stage in our intervention involved advocacy actions that were carried out once we had the results of the monitoring process. These were done through the drafting of a plan that included actions to be implemented. Some of these actions were an analysis of political forces, and the constructions of alliances with political stakeholders such as members of parliament or house representatives. We also promoted the use of mass media such as newspapers and radio. In each of the six municipalities we worked with, we had monthly meetings to agree on the actions and then review the outcomes. In 2010 we produced newsletters and radio shows through close collaboration with community partners. These resources are readily available at our website.

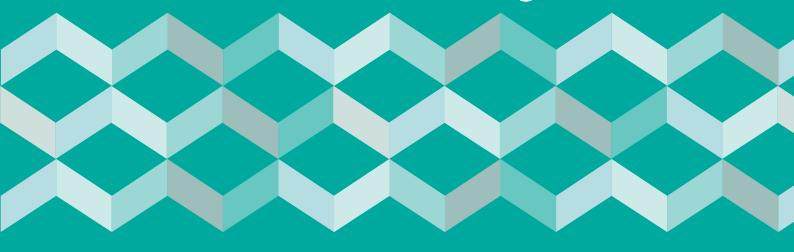
#### THE ROLES OF OUR PARTNERS

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

## Chapter 2

## Problem solving and community monitoring:

Reflecting on our strategies, accomplishments and challenges



I feel this is an awakening for all of us; we know that it's possible to demand our right to health and we have seen that change is possible.

- Male community member

#### CHANGES IN POWER RELATIONSHIPS

As a result of our intervention, we found that community leaders were now able to present analysis of local health conditions to health and municipal authorities. The presentations came with clear and well-defined demands for changes and improvements. We have seen positive changes in the functioning of the health systems, even though the project was implemented recently. For example, the municipal governments have increased the funding for fuel to operate the ambulances for emergency transport such that families do not have to bear the cost of transporting the patients to the health centre. Contracts made to outsourced care providers are terminated, as community monitoring was able to identify corruption and ill practices in the system.

With regard to health facilities, the working hours have been expanded along with increase the number of health personnel. The number of complaints about mistreatment to patients has significantly decreased. While these accomplishments speak for themselves, we share the voices from our community partners:

'I feel this is an awakening for all of us; we know that it's possible to demand our right to health and we have seen that change is possible'. Male community member

'Through the training and monitoring system we are now able to discuss with doctors and municipal authorities about the problems with medicines and personnel in the health center and health posts. Before that, we had to accept that health services were almost never there and we thought there was nothing we could do about it'.

- Female community member

#### **IDENTIFIED CHALLENGES**

This is a list of the identified challenges and the limitations we found:

- Municipalities need to have an involvement with the project, and we selected
  those who did. This is a bias because municipalities that did not express any
  interest may pose more of a challenge and resist our intervention more than
  those who are open to it.
- We had delays in the planning and implementation of our activities. The first phase took longer than we had planned because we had problems with keeping community members in the training process. High rotation levels did not let us advance as fast as we would have liked to.
- The high turnover of community members and members from the municipal-level commission had a negative impact on the second year of the project.
  We needed to change strategies and we had to create parallel health commissions in the community. This means that we did not always work with the community-level social development councils or with people from the COMUDES. We found that these people were more stable in their functions. We did manage to integrate the commissions with the already existing council scheme.

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- Some municipal authorities resisted the growing participation of community members.
- The results from the first phase of the project were obtained, thanks to the strong capacity building and guidance we had with the health commissions. The presence of us as external stakeholders was necessary. This is because as outsiders, we were not subject to the same pressures of other stakeholders and we were able to use this as a way to provide negotiation skills and to lead by example. This is a limitation since it can hinder a replication process. This limitation and the intensity of the coaching that is needed were underestimated in our original plan.
- It was not always easy to balance good relationships with municipal authorities with autonomy for community heath commissions.

#### LESSONS LEARNED

PAR is more than just a research approach; it is a way to promote change in communities through adult education and the generation of political action. While we decided on using PAR because of its capacity to generate knowledge, our experience has shown the following things:

- The participation of community members provides legitimacy to our research findings.
- This process is one that helps to empower community members.
- Through PAR we might have an entry point that generates actions on other social determinants of health.
- PAR is also relevant in multidisciplinary teams and by including social scientists and public health experts we were better able to work and implement our project.

It is also crucial to facilitate alliances between all the stakeholders so that there is inclusion in these processes. Rural community members have historically been excluded from these processes, and frontline health workers often face the same degree of exclusion from the health system. The empowerment of both frontline workers and rural communities contributes and promotes change.

Finally, it is important to be aware of the complex nature of health politics and power relationships that happen at all levels of policy planning and implementation. Demanding transparency and accountability from stakeholders that may have vested interests in policy-making processes might probe hard and block the tackling of inequities in health and power at all levels.

#### SUSTAINABILITY OF THE PROJECT AND ITS OUTCOMES

While this write –up was written, our project had attracted interest from other donors. This has allowed us to secure funding until 2015. In addition to our international funding, national NGOs and government agencies with a mandate to promote social participation have also shown interest in our work. Up until now, our approach has shown that minimal external financing is necessary, specifically in the capacity building

stages. Most of the civil society organizations we work with are already engaged in working in the municipalities where we ourselves worked, and this has greatly reduced 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 levels of resources that rural citizens have achieved through their demands and expanding the social mobilization to act upon other social determinants of health like food security or education.

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