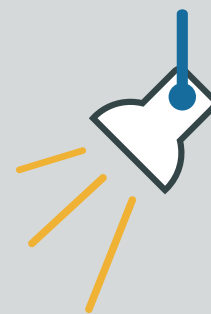


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Accountability Note



Defending the Right to Health in Guatemala: Reflections of Two Indigenous Women on the Frontlines

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Paulina Culum
Julia Fischer-Mackey



About Accountability Research Center (ARC)

The Accountability Research Center (ARC) is an action-research incubator based in the School of International Service at American University. ARC partners with civil society organizations and policy reformers in the global South to improve research and practice in the field of transparency, participation and accountability. For more information about ARC, please visit: www.accountabilityresearch.org.

About Centro de Estudios para Equidad y Gobernanza en los Sistemas de Salud (CEGSS, Center for the Study of Equity and Governance in Health Systems)

CEGSS is a civil society organization that implements applied research, capacity-building and strategic advocacy around access to health affecting indigenous and other marginalized populations. During its 10 years of existence, CEGSS has successfully evolved from an initial focus on academic research to an action research approach that engages with grassroots organizations, policy-makers and academia. The organization also evolved from a conventional public health team (medical doctors and PhDs) to an interdisciplinary team that includes political sciences, anthropology, social work, medicine, law, psychology, education, journalism and computer sciences. The CEGSS team is made up of 14 staff members, more than half of whom are women and/or indigenous. For more information about CEGSS, please visit: <https://cegss.org.gt/en/>.

About Red de Defensores y Defensoras Comunitarios por el Derecho a la Salud (REDC-Salud, Network of Community Defenders of the Right to Health)

REDC-Salud is a network of 140 volunteer health defenders who were chosen by their communities to defend the human right to health. The defenders, organized in 2008, are active in 30 municipalities in 5 departments of Guatemala, and they meet annually to share learning, coordinate and strategize. REDC-Salud members engage in capacity building in human rights and the country's legal frameworks for citizen participation, monitoring techniques, and negotiation and advocacy skills, and provide supportive accompaniment to community members seeking health services. For more information about REDC-Salud, please visit: <https://vigilanciaysalud.org/>.

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ARC publications serve as a platform for accountability strategists and researchers to share their experiences and insights with diverse readers and potential allies across issue areas and sectors. These publications frame distinctive local and national initiatives in terms that engage with the broader debates in the transparency, participation and accountability (TPA) field. Research publications include brief *Accountability Notes*, longer *Accountability Working Papers* and *Learning Exchange Reports*.

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Versión en español

Una versión de este *Accountability Note* en español está disponible aquí: www.accountabilityresearch.org/publications.

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Disclaimer

The findings, interpretations, and conclusions expressed here are those of the authors.


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A Note about this Publication and Authors

The Accountability Research Center has partnered with CEGSS and REDC-Salud for several years to support accountability work in Guatemala's health system. Julia Fischer-Mackey, an ARC staff member, first met Paulina and Benilda when visiting Guatemala for REDC-Salud's annual assembly in December of 2017. She then engaged them in a series of conversations during their visit to Washington DC in October of 2018. This *Note* is based on excerpts of those conversations, which Julia had transcribed and then organized by theme. Additional sources were drawn upon to explain particular issues. This is the first interview-based ARC publication, aiming to bring the voices and insights from action strategists to global conversations about accountability.

 **Paulina Culum** is a renowned indigenous community leader from San Pablo la Laguna, Guatemala. She began participating in different arenas, including in a literacy campaign, when she was 13 years old. In 1998 Paulina was a founding member of the organization Women Weaving a Good Life, which works on women's rights, access to land, defense of territory, and food sovereignty. She has participated in the Peasant and Indigenous Women's Association (RECMURIC) and in 2014 she began working with the Network of Community Defenders of the Right to Health. She has participated in forums in Colombia, Venezuela, El Salvador, USA and Mexico.

 **Benilda Batzin** comes from San Pedro La Laguna, has a bachelor's degree in Social Work and has experience working on various community development and environmental protection issues. She serves as a liaison between CEGSS staff and the defenders, providing accompaniment and capacity building to defenders, and coordinating strategy to achieve health rights for indigenous populations in the department of Sololá and throughout Guatemala. When this interview was conducted, Benilda was working as an advisor. In October 2019, the CEGSS staff elected Benilda to succeed CEGSS' founder, Walter Flores, as executive director of the organization, effective January 1, 2020. She also continues to advise the health defenders in Sololá.

 **Julia Fischer-Mackey** is a researcher with the Accountability Research Center who received her PhD from American University's School of International Service. She has conducted development program research and evaluation in several countries, including in Guatemala. She is interested in questions of power, knowledge and evidence, and has experience with thematic areas including health, gender, and environmental justice.

Summary

Defending the Right to Health in Guatemala: Reflections of Two Indigenous Women on the Frontlines

The Guatemalan Constitution guarantees the right to health for all Guatemalans, but indigenous citizens face multiple barriers in accessing public health services. In addition to the transportation challenges and under-resourced facilities faced by rural communities around the world, indigenous Guatemalans face racial and linguistic discrimination and corrupt officials demanding fees for free public services. Two organizations that formed to combat these problems are the Center for the Study of Equity and Governance in Health Systems (Centro de Estudios para la Equidad y Gobernanza en los Sistemas de Salud, or CEGSS) and the Network of Community Defenders of the Right to Health (Red de Defensores y Defensoras Comunitarios por el Derecho a la Salud, or REDC-Salud). REDC-Salud volunteer health defenders educate citizens about their rights, provide accompaniment to patients, monitor health services, and advocate for health system improvements. The CEGSS team provides technical support and capacity building to REDC-Salud members and coordinates monitoring and advocacy at the municipal, departmental and national levels.



Left to Right: ARC Managing Director Angela Bailey, Julia Fischer-Mackey, Paulina Culum, Benilda Batzin, and ARC team member Suzan Osman. Washington, DC. November 2018.

In the following interview excerpts, Benilda Batzin of CEGSS and Paulina Culum of REDC-Salud describe how they work together to make government health systems more accountable to all citizens. Benilda and Paulina’s unique approach involves mobilizing established community leaders to engage on health access issues at multiple levels of government and forming alliances with groups including the national Human Rights Ombuds. As Maya Tz’utujil women from Sololá, Western Guatemala, Benilda and Paulina faced multiple barriers to civic participation and leadership. And yet, their commitment to bringing positive change to their communities have led them to initiate and join organizations and acquire new skills. Those skills and leadership qualities have been widely recognized and resulted in formal and informal opportunities to lead: Benilda was elected by her colleagues to become Executive Director of CEGSS and was invited to give testimony at the United Nations General Assembly; Paulina chairs her town’s Community Development Council, has served as the national chairperson for the Tz’utujil Women’s Organization and mentors young female activists.

This *Note* highlights strategies and accomplishments of these leaders and their organizations while reminding us of the work yet to be done by activists and their allies to defend the rights of all Guatemalans.



Health Defenders Rosa Sojven, Paulina Culum, Glora Ujpán and Benilda Batzin. 2017. Credit: Sandra Sebastián.

A community leader with a deep personal commitment to justice builds respect and influence over time, but this also involves personal risks and sacrifices



Julia: Paulina, can you describe to me how you became a community leader, and how your leadership evolved over time?

Paulina: I began when I started the sixth grade of primary school. The government made the students in the sixth grade give classes to women who didn't know how to read and write, because there was a lot of illiteracy. But I didn't have the necessary knowledge, as I hadn't even completed sixth grade.... but I started teaching with the teacher beside us students. The teachers gave us the answer when we didn't know something and corrected our mistakes.

After the Peace Agreements were signed in Guatemala [in 1996] a lady from San Juan La Laguna arrived in search of women's organizations but there weren't any [back then]. There were no women's organizations. So she came to my house and told me women had referred her to me. I told her that I taught literacy skills but it is not an organization. "Oh, but you work with women," she said. "Yes, with women," I replied. So we tried to set up an organization with another woman. I didn't have the necessary knowledge and I was embarrassed to speak because I wasn't used to that—because women are not supposed to do that. But we did begin to organize... and we went to San Pedro to listen to talks about self-esteem and the role of women. An assembly was held to decide the name of the organization. It was named Organización de Mujeres Tz'utujiles (Tz'utujil Women's Organization), as we were located in the basin of the lake but in the Tz'utujil area....

Box1. Racist abuse of indigenous people by public health care workers in Guatemala

Health inequalities disproportionately affect indigenous people in Guatemala. Previous studies have noted that the disadvantageous situation of indigenous people is the result of complex and structural elements such as social exclusion, racism and discrimination. In rural indigenous municipalities of Guatemala, discrimination while seeking health care services in public facilities was ranked among the top three problems by communities and that should be addressed by social accountability interventions. This study aimed to understand and categorize the episodes of discrimination as reported by indigenous communities. A participatory approach was used, involving CEGSS's researchers and field staff and community leaders. Focus groups in one rural village in each of 13 different municipalities were carried out to identify instances of mistreatment and to document testimonies of those who were affected. The study identified 132 episodes ranging from indifference to violence (psychological, symbolic, and physical), including coercion, mockery, deception and racism. Participants described different expressions of discrimination and mistreatment associated with poverty, language barriers, gender, ethnicity and social class. Addressing mistreatment in public health settings will involve tackling the prevalent forms of discrimination, including racism. This will likely require profound, complex and sustained interventions at the programmatic and policy levels beyond the strict realm of public health services.

Source: Summary of Cerón et al. (2016). "Abuse and discrimination towards indigenous people in public health care facilities: Experiences from rural Guatemala."



Citizen monitoring and a meeting with the Director of the Sololá Department Hospital. Left to right: Joaquín Juracán, Santiago Simón, José Ulario, Catarina Ixtós, Francisco Tos, Rosa Sojven, Juana Ajquí and Benilda Batzin.

A board of directors was chosen and I was chosen as chairperson. When I was elected I began to play a [leadership] role in my community because I already had some skills.

Thank God my parents and siblings always supported me. They never said: “No, women shouldn’t do that.” Thank God I always had the opportunity to participate. I subsequently began working at a national level as the chairperson of the women’s organization. Later, we met and began working on healthcare issues. From the start, our organization has focused on women’s rights, violence, and how to improve our lives. That includes everything: healthcare and education. Unfortunately, we never had enough resources to work on this and one has to address one issue at a time. We subsequently sought other opportunities to work on each of these issues. At a national level, I belong to an organization called “Tejiendo Fuerzas para el Buen Vivir” (Weaving Forces for a Good Life), which focuses on four key issues: land access for women, defense of territory, food sovereignty, and ending violence against women.

Thanks to Benilda’s support, who was my tutor, I also learnt about certain legal provisions, about healthcare, law and information technology, too. I acquired these skills and shared them with other organizations so that



Paulina Culum speaking with Health Services Secretary Amanda Mazariegos while monitoring the stock of medicines and supplies at the San Pedro La Laguna health center. 2017. Credit: Sandra Sebastián

others could benefit from them, too. It was easy for me to share those skills because others had skills that were also useful for us. That’s why working together has always been very important to me and to this day I continue to foster collaborative work.



Using community radio to promote knowledge of human rights and the legal framework guaranteeing the right to health. Paulina Culum, Juana Ajquí, Catarina Ixtós and María Tzaj. August 2018.



Paulina interviewing a user of health services in San Pablo La Laguna to identify needs and problems, but above all to understand the quality of care provided by the health staff. 2019.



Paulina speaking on a panel about grassroots accountability work at the Global Partnership for Social Accountability at the World Bank. Washington DC, 2018. Left to right: Jonathan Fox, Nani Zulminarni, Paulina Culum, Joy Aceron, Wunna Htun.

Box 2. Criminalizing Community Leadership and Public Service Monitoring

In early 2018, members of staff of the public healthcare center in Sololá filed a legal complaint against community healthcare defender Paulina Culum for alleged threats and intimidation. This criminal charge was levied against Paulina because she was part of citizen monitoring efforts advocating for the end of discrimination and abuse towards indigenous people who use local healthcare services.

Those who filed the complaint against her claimed they had been coerced and had suffered discrimination by other healthcare users as a result of Paulina Culum's alleged "incitement." The health center staff targeted her as an individual, even though she was acting on behalf of the community members.

The Attorney General's Office summoned all parties involved and after failing to reach an agreement, it began to investigate the facts and analyze the evidence. After almost a year, the claim was rejected as no evidence was found to support the claims against Paulina Culum. This case demonstrates both the risks faced by defenders and also how the elite in Guatemala use the legal system to repress the Constitutional right to civic activism. Thankfully, with the legal support provided by CEGSS and other partners, the case was dismissed for lack of merit.



Defenders of Sololá Department presenting their 2019 activities, challenges, and accomplishments at the National Assembly of the Network of Community Defenders of the Right to Health. Left to right: Rosa Sojven, Benilda Batzin, Juana Ajuquí and Paulina Culum. December 2019.

Capacity building, strategic organizing, and using different approaches to government officials takes time and a deep understanding of people and context



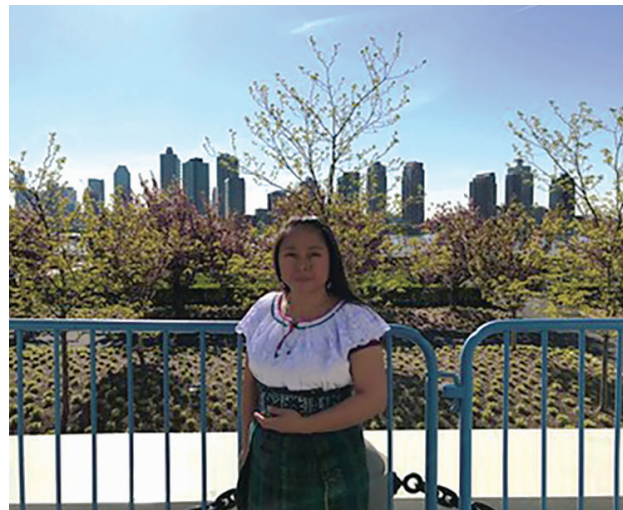
Julia: Benilda, What's your current position within the CEGSS and the REDC-Salud network?

Benilda: I continue to work as a tutor and healthcare defender, providing the REDC-Salud network in the department [first-level administrative division of Guatemala] of Sololá with support and technical advice. In 2020 I will become the Executive Director of the Center for the Study of Equity and Governance in Healthcare Systems (CEGSS). This is a strategic change to allow the staff to lead the organization and also bring to bear the experience I have gained over the past six years. Also, as an indigenous woman, I have the capacity to lead the organization and I'm familiar with indigenous communities' problems as well as possible solutions.

Julia: Benilda, can you explain your strategy for developing the health defender network in Sololá? How did you enlist existing leaders in the work of the REDC-Salud?

Benilda: I have seen people with different characteristics, leaders, people who already had a track record within their communities, as well as people who are at the early stages of their track record. There are different leadership processes within the REDC-Salud.

Initially, when we began to organize and strengthen the healthcare defenders, who are male and female community leaders in this case, we visited municipalities so that we could strengthen the Healthcare Commission. But once we reviewed what they were actually doing we realized that the commission existed on paper but did not actually address all the issues that a Healthcare Commission should. Our work is not only to carry out social accountability, but to address other issues



Benilda outside the United Nations in New York before giving testimony about the health access needs of indigenous populations in the General Assembly.



Benilda Batzin, visible on the large screens, giving testimony about the health access needs of indigenous populations in the United Nations General Assembly. April 2019.



At a community meeting with health center staff organized by REDC-Salud in San Pablo La Laguna, a woman asks that the health center staff be accountable to community members. 2017. Credit: Sandra Sebastián

relating to health in the municipality and community in a comprehensive manner.

It was necessary to create this Healthcare Council, led by citizens and community leaders. We began working on the selection and organization process. I personally visited the municipalities, and thanks to the support of a number of leaders that we had already identified before this process began, we produced a map of political actors.

We set out to produce a map of political actors so that we can go to the community and explain the project to them. [We said] How will it work? What will be done? The leaders who accompanied me already had skills, they were recognized in their municipalities and within various organizations. The leadership process does not have a final stage, it is progressive and it is currently in progress. We can't say it has come to an end.

These leaders accompanied me so that I could visit other leaders whom they knew because they had worked together, because they were friends or because they had heard about those leaders. We sat down with them and made plans. "Who are the leaders in this municipality?" and we made a list. "Which leaders do you know in San Pablo La Laguna?" We began working in San Marcos La Laguna, Santa Cruz La Laguna and Concepción Sololá.

Once we had drawn up a list of names, we told them about the project. We told them: "Look, we would like to do this," rather than saying "Look, you need to join this." No. We said: "Look, we want to do this. How could you help us to reach this goal?" We began to visit each and every male and female leader and told them about the project. We had direct contact with them and it was much better because we took into account their doubts, recommendations and suggestions.

This is very important to us because we're in another community—this is not my community so I have to see what's going on and understand the context of the municipality, of that community. Most of those leaders told us it would be best to hold an assembly with the various organizations or civil society groups that already exist and that was convened.

In some places, the municipal authorities facilitated coordination. In others, we had to visit them personally and say: "Look, we're going to hold a meeting because we also have the right to organize as a community and as a municipality."

Julia: How did community defenders learn they had the right to oversee public healthcare services?

Benilda: First, health rights defenders organized at a municipal and departmental level. Secondly, they underwent training on issues such as social accountability, public healthcare policies, citizen participation, human rights and the legal framework for healthcare services. They also attended workshops on how to use tools to gather evidence based on their oversight of the healthcare services. Thirdly, while they underwent training, they conducted fieldwork (oversight of healthcare services) in order to put into practice what they had just learnt.

Julia: How do defenders oversee the healthcare services? What do they do with the evidence they collect?

Benilda: First of all, in each municipality, the defenders organize and plan the specific dates on which they will visit the healthcare services (healthcare outposts, centers and/or hospitals), so that they can prepare all the materials required to exercise their oversight duties. They arrive at the healthcare service, meet with the person in charge in order to inform them about the work they are about to carry out, and then

they interview the users as well as the healthcare staff, in order to identify needs and problems.

Once they conclude their oversight work, they meet with the directors of the healthcare service to inform them of the results of their oversight work and make the necessary recommendations to solve the problems identified. They also produce a written report including the means used to exercise this oversight (photographs).

Julia: I understand when you started working in Sololá, community- and municipal-level health councils existed on paper, but they often were not doing very much to ensure quality health care. Can you explain what you did?

Benilda: I began working with the CEGSS five years ago. Sololá was the last department to join the REDC-Salud. The network was already present in the four departments but it was broadened to include Sololá. So I began the organization process... We trained the Healthcare Committees and Councils on healthcare issues, human rights, citizen oversight, and the legal framework: both national and international that



The doctor in charge of the San Pablo La Laguna health center, Dr. José María Barrios, tries to defend himself from accusations of the meeting participants. Next to him are Paulina and Rosa Sojven, who are moderating the meeting. 2017. Credit: Sandra Sebastián



Defenders from the municipalities of Santa Cruz La Laguna, Concepción, Nahualá and San Pablo La Laguna, Sololá reflected on their work during 2019 in order to establish their goals, objectives, activities and expected challenges for 2020. Left to right: Cruz Santos, Francisco Tos, Santiago Simón, María Tzaj, Paulina Culum, Mario Juracán, Rosa Sojven and Juana Ajquí. December 2019.

protects freedom of information, citizen participation and social accountability.

Julia: Can you explain how the REDC-Salud works at many levels with the government and other entities?

Benilda: The REDC-Salud network has links, alliances and mutual coordination with the municipal healthcare commission that operates in every municipality. The council and the REDC-Salud network should coordinate actions and work jointly. But most healthcare commissions in Guatemala only exist in paper, their members have been named but they don't fulfill their duties. The REDC-Salud network strengthens their work and also exerts pressure to ensure that the commission, which has decision-making powers, does its job.

The REDC-SALUD network also coordinates actions. It has a partnership with the Community Development Council.¹ Guatemala has an Urban and Rural Development Council Act. According to the law, councils are divided into five tiers. The first, the community tier, includes the Community Development Councils (COCODES). Then there are the Municipal Development

Councils. At the departmental tier, there are the Departmental Development Councils (CODEDES), and then there is the National Development Council. Under this act, these spaces should include civil society representatives, government representatives and various authorities, depending on the tier.

So here the REDC-Salud network works together with the Community Development Councils (COCODE). The councils' role is to study, analyze and research the communities' problems. Based on that, they work with the communities to establish priorities. Those priorities are presented to the municipal council, which takes the necessary actions or implements projects or programs to address the issues.

The REDC-Salud network coordinates actions with the community development councils and is part of the Municipal Development Council (COMUDE). (As I previously mentioned,) I can participate in those councils although I can't vote because I'm not registered. The COMUDE addresses education, healthcare and infrastructure issues and decides which problems to prioritize in order to implement a project or program. Although I participate I can't say I support the council

because my vote doesn't count. Paulina's vote counts because she's a member of the REDC-Salud network and also chairs the COCODE. She has several roles in her municipality.

We also work closely with the Community Councils for Food and Nutritional Security (COCOSANES). These councils specifically address the malnutrition issue in Sololá and at a national level. In Sololá, in particular, there are several municipalities with high levels of malnutrition, so we coordinate actions with these councils as this is a health issue.

We work with midwife organizations. Midwives are crucially important to our work because they serve patients. But they also have direct contact with healthcare staff. So they can help us to identify situations and we can help them, too, with any issues they might be facing. We're helping midwives to organize in a department where they suffer from a lot of discrimination. Doctors don't value their ancestral role. They say: "They (midwives) don't know anything. They shouldn't be here. What they do has no scientific value." They suffer discrimination. We're currently working on this issue at a national level.

The Network also works very closely with them, with healthcare workers so that they can also make decisions and solve certain problems. There are many more grassroots community, peasant, artisan and women's organizations in the municipalities. Working with this grassroots base is a great strength.

At a departmental level, the REDC-Salud network coordinates actions with hospitals as well as the Healthcare Area Directorate. We coordinate our work and we have spaces for dialogue. We have a very good relationship with the hospitals in Sololá, with the hospital director.

We've made progress with her as well as the Healthcare Area Directorate, which is responsible for healthcare centers and outposts. That's where decisions regarding various programs or the implementation of various programs are made based on public healthcare policies. It receives funding from the Ministry of Health to implement these actions. This is where decisions regarding health centers and health posts are taken.

A departmental healthcare commission is needed, with the participation of all of the bureaus and organizations that work on healthcare issues in Sololá's 19 municipalities. This includes civil society organizations, midwives and healthcare workers. The various healthcare and environmental protection commissions must participate.

Julia: Paulina, why do you think it's important for defenders to wear their REDC-Salud vests?

Paulina: First, to be honest, for us as defenders, it's important for us to wear the vest and a badge that identifies us as healthcare defenders. Second, when we begin our work, they always ask: "Do you have ID? Why are you here? What are you here for?" Third, it's important to wear a vest because when we focus on oversight work and attend meetings, the vest identifies us as members of the network. Wherever I go, different organizations identify me: "Oh yes, they belong to the REDC-Salud network. They're wearing a vest," and they introduce themselves. The importance of wearing a vest. It's also important because we represent an organization. For example, if we're not wearing a vest, they ask us: "which organization do you belong to?" But when we're wearing a vest no one asks us... The truth is I was left with many questions regarding the type of support they expected from us but when they realized we were really organizing with the communities, they said: "This is not just some agency, it's the community, its citizens."

Box 3. How strategic collective action of REDC-Salud defenders achieves results

A qualitative comparative analysis (QCA) study published in 2019 found that to overcome the power asymmetries that marginalized groups face when engaging with authorities, iterative processes of network building and participatory monitoring as well as persistence in their demands are critical. The study identifies three pathways of collective action through which citizen-led initiatives bolster their power to engage and negotiate with authorities and bring about solutions to health system weaknesses.

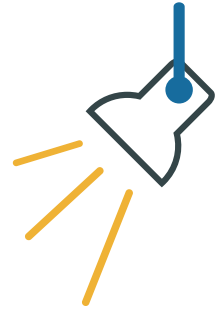
In Concepción municipality in Sololá, a strong network of community activists and leaders that regularly engaged with relatively open municipal government officials enabled positive changes in the health system. These findings demonstrate the potential of collective power generated by the actions of citizen-led initiatives to enable marginalized populations to hold authorities accountable for health system failures.

Source: Summary of Hernández et al. (2019) "Pathways to accountability in rural Guatemala: A qualitative comparative analysis of citizen-led initiatives for the right to health of indigenous populations."



The signing of the Memorandum of Understanding between CEGSS, REDC-Salud and the Human Rights Ombuds of Guatemala (PDH) for the joint monitoring of public health services. Left to right: Daniel Otzoy, legal representative of CEGSS, Lic. Jordan Rodas, Human Rights Ombuds and Ms. Paulina Culum, defender of the right to health. June 2019.

Confronting marginalization involves attention to multiple forms of discrimination and the importance of people's lived experiences



Julia: What role does language play in your work with different communities?

Paulina: Well, I, personally, had to learn two more languages in order to meet the needs of our organizations in various municipalities. I am a Mayan Tz'utujil woman. My native language is Tz'utujil but now I can also speak K'iche, Kaqchikel and Spanish. So yes, it's very important to speak our languages because illiteracy is prevalent in most parts of my country. Not everyone can read and write. That's why it's important to speak an indigenous language. On the other hand, our mother tongue is an indigenous language, because we start learning at home, with our families. And then, when we begin school, we learn Spanish there. So the first language we have to learn in order to help other people is our own language. And it's very important because we've managed to carry out oversight visits to the departmental hospital because no one speaks an indigenous language there even if those who work there are Kaqchikel, Tz'utujil and K'iche. They don't speak their native languages and we've managed to get them to speak their Mayan language with the hospital, health-care center and healthcare outpost patients.

Julia: Can you give an example of how indigenous language speakers' right to health can be protected through health center changes?

Benilda: Hospital workers didn't wear ID badges so we didn't know who they were. We told the hospital director and now they wear badges. She made that happen. Furthermore, most of the indigenous women who work there wear a uniform that consists of pants and a blouse.

We used to tell the director that we didn't know where they were from so that we could speak to them in their indigenous language. Now the women who work in certain areas also wear their traditional indigenous attire. Now that we know where they come from we approach them and speak to them in their indigenous language. There have been a number of changes. They may seem insignificant but they're very important for us because they change many things.

From our point of view, many things change during our experience working with the users. Sometimes those processes evolve quickly and other times they grind to a standstill, but we're making progress. We need to continue gaining strength because it's a cycle—strengthening REDC as an organization, training, field-work, results analysis, advocacy, follow-up, evaluation, and then we start again.

Julia: What are the challenges that women in your communities face in taking on leadership roles? What are you doing to support and build the capacity of the next generation of women leaders?

Paulina: At first, when I started, I found it very hard because no one taught me. On my own, I started to learn how to do advocacy, influence, how to take part in meetings. I didn't have that experience and it was quite hard for me. I don't want young people to go through that. When I began attending meetings, I was afraid. For example, I didn't know what to say and I didn't know what people were talking about.

Things are different now. I have teaching experience. Firstly, I have to know about women's rights. Secondly, I need to know about advocacy, and thirdly I need to

know about self-esteem because without that I'm always going to be stuck in the same place.

Women, young and old, often face discrimination. Firstly, because we wear traditional Mayan attire. Secondly, because we speak our language. Thirdly, because we're illiterate. We need to be aware of those three issues. I don't want young women to suffer what we have suffered along our path to leadership.

Being a leader doesn't mean you're going to earn money. It doesn't mean you're going to get paid. I regard leadership as voluntary work. No one can support us. Occasionally, we receive financial resources but that's very rare.

Why is it so important for us to have more female leaders? Because that's the only way we can support other women who are illiterate. A female leader becomes a spokesperson for the rest. The leader must be informed, she needs to know what's going on in the community.


Later, after some time, all the women trust the leader. I always tell them. "If I'm the only one who takes on this role, who will continue my work?" That's why it's very important to work with young people. But how can we do this? One of the greatest obstacles is the lack of resources, the fact that we don't have an office or a meeting room where we can host training sessions and all that.

It's important. For me, it's interesting to begin training young women to ensure we're heading in the same direction. They shouldn't be heading down one path while we head down another. We shouldn't be divided.

That's the idea, that's our experience and I'll uphold that. We need to pass on the responsibility to them (young women) so that they continue to learn along the way.

As I mentioned before, if I pass down all of my knowledge to them, they will find it easier to attend a meeting, to carry out advocacy work. They won't suffer like we did because no one gave us those guidelines, no one told us how to do things but for me it's very important to hand down that experience so that everyone can start learning.

I'm currently mentoring a young woman. I teach her everything. As technology facilitates this, she writes to me: "Look, they're asking me about this but I can't do it--" I tell them: "You have to do this and this," I reply, and that's how we've managed. It gives me satisfaction because now she's part of the board of directors of a departmental organization that works to eradicate violence against women. Now she's going to receive training on victim support. I'm glad she's already started. I wish others would follow her footsteps.

 **Benilda:** We also address other issues such as self-esteem and women's participation in these groups [of defenders]. Half of the members of the REDC-Salud in Sololá are women, unlike other departments where most members are men. The idea that women shouldn't participate in these spaces still prevails.

Working at different levels of government can address bottlenecks and have the potential for large-scale change



Julia: Can you describe how you work at multiple levels of the government?

Benilda: If there's a problem that's not within the district's authority or within the authority of the municipality, then yes, it can be addressed at a departmental level. It works like a chain. There are innumerable problems that are not resolved at this level. Our first point of contact is the municipal level. We give them a reasonable timeframe and if there's still no answer then we have to move on to the next stage and go to the Healthcare Area Directorate. And if there's nothing we can do at a departmental level, we have to move up to the national level and go to the Ministry of Health.

There was also a lot of openness with regard to certain services. "Welcome, let's get down to work. Let's work together," they said. Yes, that happened in most of the five municipalities with regard to most issues with the exception of two or three services where they didn't regard our participation favorably because they believed our participation would affect them. But we visited the healthcare clinics and presented our work.

At first, it was something new and strange for them because maybe they had never been subjected to citizen oversight. Maybe they had only been subjected to professional audits that requested documentation containing quantitative data. "We need this and that and here it is," they said. But I think they didn't expect citizens to show up to find out what was going on but since that's a human right, a citizen right, they couldn't stop us from accessing those clinics.

We got down to work and when we presented results they told us: "Well done, no one has ever done that before. That's the only way we can produce better work,"

they told us. But on the other hand, we heard them say: "Why did they come here? What were they doing? They're just getting in the way," because although there are many public officials who work well there's always someone who doesn't do their job properly and it only takes one person who doesn't work well for us to produce a report on a specific service.

We started to coordinate [actions], we took on a management role working with them as health authorities, and we worked on improving the service provided based on our oversight role. We accompanied the local authorities to the town hall, we wrote request letters that were signed by the doctor, we sent requests, and the doctors even accompanied us. It all worked really well.

We worked with a number of municipal authorities, in towns such as San Pablo La Laguna and managed to get them to allocate funds for the purchase of medicines, which was the most serious problem that people had highlighted, that they didn't have enough medicine to treat their illnesses. The issue was addressed and the municipal authorities purchased the medication. The REDC-Salud network even accompanied and oversaw the process of the health staff purchasing the medication.

We were working in a community and all the key actors were there. The medication arrived and everything was working well. We followed the same path to secure an ambulance. We worked with the municipal authorities, with the community and health workers. The service that people received was improving and there was good communication with the healthcare staff.

Time went by but not everything was running smoothly. As always, some things worked well and others didn't.

It turns out that sometimes the right members of staff were not being hired and those hired didn't meet the requirements. We highlighted that.

As a result, one of the service directors no longer approved of the REDC-Salud because he thought it had a negative impact on the staff, leading staff to be dismissed or moved to a different position. However, that will depend on the quality of their work. If they're working well there shouldn't be a problem but if they're not working well something should be done. As a result, coordination, communication and collaboration between them was weakened for one of the services. Nevertheless, the REDC continued with its work.

We have also gained more space at a departmental level. Working with the health authorities, we have established a negotiating table where we introduce ourselves, where we arrive and tell them: "Look, this is what's going on." But things move very slowly at a departmental level. At a local level, problems have been solved in the short term, but processes have been far longer at a departmental and national level.

Julia: Can you give an example of how your work accomplished something challenging through strategy and persistence?

Benilda: The healthcare outpost in a village called Patzutzún, one of Concepción's rural communities, covers four other communities. The problem there was that there was no ambulance, there was no emergency transportation. Before we started working as a Healthcare Council, two maternal deaths had been reported because [the patients] were not taken to hospital on time. The community has a number of vehicles but people don't have any money to pay for the ride. So we prioritized their problems and they told us: "We need an ambulance." That may not be the solution, but it's necessary. Let's get down to work. Where shall we go? What shall we do? You need to come up with ideas because we're not going to impose anything. Because there are experienced people and there are people who lack experience but also have ideas to contribute. We gathered people and asked them: How can we achieve this?

Firstly, we prioritized the absence of an ambulance. What did we do? We held a community assembly where

we asked people what they regarded as their number one problem. There was a lack of ambulances, of medicine, and other services. But we prioritized that and after the assembly, we met as a Healthcare Council in order to plan what we had to do. During the assembly, minutes were written up recording that people had mentioned that need. Everyone signed the minutes at the end of the assembly. Different groups stamped the minutes agreeing that it [the ambulance] was needed and that people had requested it. The negotiation started. We went to see the mayor, we went to see the district directors who are responsible for making any decisions, as well as the healthcare area director. We got down to work. The mayor told us: "You need to manage this because you're the community and people are more likely to listen to you than to the authorities." We made the petition, not once, but several times. We delivered petitions, we spoke to people, and we carried out several activities.

When we went to see the area director, who's in charge of the department, he told us it was impossible to provide an ambulance for the health posts. According to the Ministry of Health's internal provisions, health posts shouldn't have an ambulance. Only healthcare centers in the municipal center should have one because they're under the director's responsibility. But let's find a solution because the service is needed. People are dying because there's no transportation to take them [to hospital]. We insisted and insisted until a specific case arose that was analyzed and it was concluded that the problem existed. Then the departmental director sent the request to the ministry, it was no longer us. He gathered all the evidence and took it to the ministry. Then he told us the ambulance would be authorized but there was no fuel and no driver, and that drivers had to meet the set requirements. We went to see the mayor and he said: "These are the requirements. There's no problem." An official document was drawn up stating that the municipal authorities would provide the fuel and would hire the driver, and that an ambulance would really be sent to the community. They could no longer say "no" because the municipal authorities were going to make a contribution and the ministry would provide the vehicle. We started to negotiate with them and reached the conclusion that the ambulance would be provided.

It was a process that took months and at one moment they felt despondent. I told them: "We have a note agreeing [to provide the ambulance] and the official

document so it's just a question of waiting. We need to be patient and perseverant and not give up."We submitted the petition in October 2014 and the ambulance was delivered to the health post in August 2015. People were very grateful. The REDC-Salud network in that community is very satisfied. They say: "Yes we can. It can be done" but we didn't achieve that overnight. But from that point onwards, they woke up and said: "If we achieved that, we can achieve more." It's Sololá's achievement and it really happened thanks to the REDC. We have some other achievements but that was our first medium-term achievement.

Julia: One thing we talk about a lot is how to achieve systemic change. As I understand it, you have cultivated a relationship with the Human Rights Ombuds' Office (Procuraduría de los Derechos Humanos, PDH) at the departmental level in Sololá. The Procuraduria is investigating problems. Also, you are influencing changes in how they monitor health systems and helping them to begin collecting information from health system users. Therefore, despite the Procuraduria's delays at forming an agreement at the national level, you have begun to

work with the government at the department level in a way that could lead to important changes. This is a novel approach—starting to make systemic change at the middle-level of a system. Can you explain how you achieved this and what your collaboration consists of?

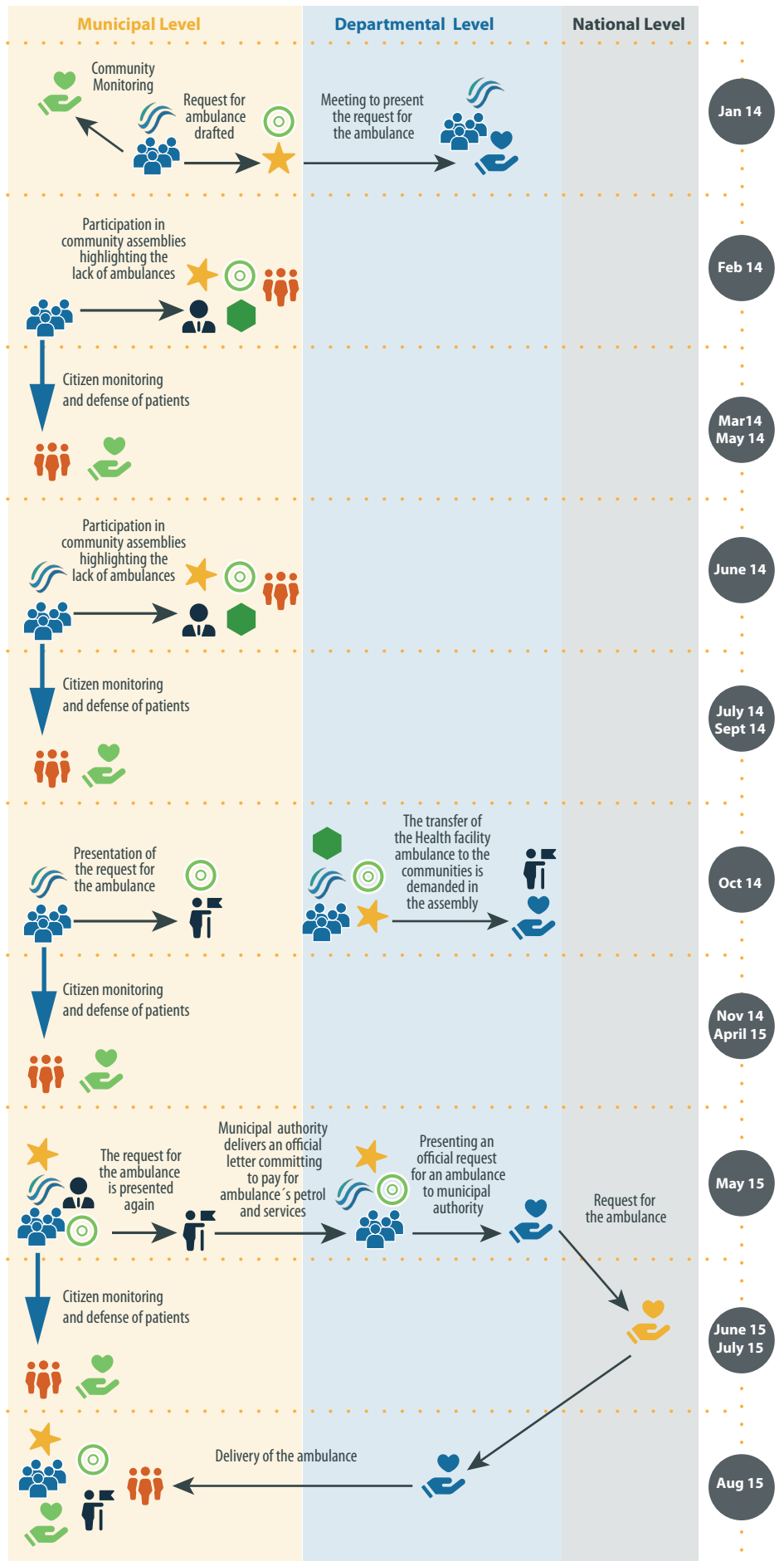
Benilda: Establishing exchanges with the PDH in Sololá was a brainchild of the REDC network. We're working on an agreement and in order to achieve that, the REDC is producing a manual jointly with the PDH. The manual includes the vision, mission, objectives, and lines of work where the PDH and the REDC-Salud network will focus their respective interventions. This can become the means to file legal complaints, report human rights violations, or crimes and [will set forth] which institutions we must take our cases to.

The REDC-Salud network presented its work [to the Ombuds' office], how it was done, the methodology used to monitor public services. They're the ones monitoring public services. As a result, we managed to get the PDH to look into the emergency transportation issue in Sololá's 19 municipalities. The REDC-Salud network



Monitoring visit at San Pedro La Laguna Health Center with PDH. Left to right: Amanda Mazariegos, Health Services Secretary; Lic. Salvador Loarca, Assistant to the PDH; Juana Chavajay and Paulina Culum, health defenders. April 2019.

Diagram 1.
The Actors Involved and the Timeframe Required to Solve the Lack of Ambulance Services in the Municipality of Concepción, in the Department of Sololá.



had already done this in five municipalities where it had coverage and said: “Things are not working here. We need to investigate this and dig deeper.” So they started digging. Now we are waiting for the results of that...

Right now, we’re looking beyond this department and we’re expanding our efforts nationwide. We’re building an alliance with the five departments. We’re even working with the Human Rights Ombuds at a national level. He seemed very interested. We’ve already explained the REDC’s work to him and he was also very impressed. At a national level, the Human Rights Ombuds’ Office is already familiar with the REDC’s work. We’ve already had a preliminary meeting with him. The Human Rights Ombuds works at a national level and has sub-offices in each department. We started at the bottom and worked our way up, with good results. Now Sololá has a strong alliance with the PDH. They, as the PDH, can file a constitutional complaint. They can have an impact at a higher level, because they can lodge complaints against the state, against the ministry...

Their role is to oversee all types of public services – education, the environment, everything. They’re the official government bureaus. We’ve established a good working relationship and good communication with them as well as a mutual recognition of each other’s work. The REDC network is present in five municipalities but they [the PDH] monitored the emergency transportation issue across 19 municipalities. We briefed them on problems in the five municipalities but [the ambulance issue] concerned them the most and they decided to conduct an investigation in all 19 municipalities. They worked in every municipality in Sololá. Now we’re just awaiting their report. We’ve made a number of findings but we haven’t had the chance to sit down and analyze the reasons behind [the problems reported]. They check the services provided and find out what’s going on with members of staff. But not all are users. Staff can submit documentation showing everything is perfect and there are no problems, that everyone gets their medication. But what do users say? Is it true or not? It’s important to establish what their perceptions were regarding user perceptions. They had almost concluded the investigation when we asked them. Did you interview some of the users? “Not yet. We still have to do that.” So they went back to the field and are halfway through that process.

Julia: What has happened with the PDH since we last talked in 2018?

Benilda: In early March 2019, we planned joint oversight activities (citizen oversight) for the first and second tier of the healthcare services (healthcare outposts and centers), where we identified problems and needs and drew up reports with the results obtained in order to conduct advocacy activities. The PDH has also carried out activities to boost the network’s capacities and knowledge regarding issues such as human rights, the legal framework and how to file a legal complaint. By June 18 this year, a memorandum of understanding had been signed by the Human Rights Ombuds’ Office, the REDC-Salud network and CEGSS in order to work together to oversee public healthcare services and begin advocacy processes with the relevant authorities. This has strengthened the advocacy and monitoring work that we conduct with the two institutions and has yielded good results.

Julia: Why do you think it is important for the REDC-Salud to have the memorandum of understanding with the PDH that was recently signed?

Benilda: It’s important because it means we’re not on our own as defenders, or as CEGSS. We already have accompaniment from the PDH and we work with them directly. Why do I believe it’s important? Because we no longer attend [meetings] on our own, we receive support from the PDH.

When the healthcare center staff see PDH officials and members of the REDC-Salud coming, they say: “Here they come.” They think the main purpose of our visit is to oversee what they’re doing. For me, the most important aspect [of the alliance with the PDH] is that we’re coordinating our work, we can identify as members of the network, and they can also identify themselves as PDH officials.

It’s important because now we’re following-up these issues at a national level and now they’re aware of the work we’re doing. We also exchanged roles. Their role is to oversee the medicine supply, infrastructure and medical staff. We, on the other hand, as a defenders’ network and as the CEGSS, exercise oversight at a more local level. That’s where we’ve identified most cases of



Health defenders meeting with Dr. Rodas, Area Health Director of Sololá during a roundtable discussion. They discussed problems with the health services and presented recommendations to address them jointly. Defenders left to right: Salvador Sancoy, Benilda Batzin, Paulina Culum, Rosa Sojven and Santiago Simón. 2017.

mistreatment and discrimination, in the first, second and third tiers of the healthcare system.

The PDH doesn't do that, that's why it's important. They've understood why oversight is important at a local and departmental level. Now it's a question of coordinating our work. That's why having their direct accompaniment is important for us.

Julia: Paulina, as a defender in your municipality, but also as a departmental representative and henceforth a national representative, following the memorandum of understanding that was signed with the PDH, why do you believe it's so important to effect structural changes at a national level?

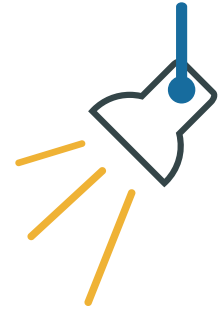
Paulina: It's very important for me as a leader because we inform [the community] and share with them all of the work that is done from above. It's important because problems are not just discussed at a national level; they're discussed from the grassroots.

My participation is very important because my fellow defenders trusted me as their representative. But it's not just a question of coming here and representing them, it's about sharing my experience.

Because really right now I'm not just a healthcare defender, I also participate in other spaces. What I do at a national level when we have a different network meeting, is share my experience with others. They find it striking because they're unaware of the problems that arise at a local level in the healthcare outposts and centers. It's very important for me, too, and I've always enjoyed helping people, not just in my municipality but also at a departmental and at a national level.

Why? Because we women have been left to fend for ourselves and solve our problems. That's why participating at a national level is even more important.

Conclusion



Julia: What conclusions would you like to share with the readers?

Benilda: My greatest personal and professional satisfaction is having reached the communities. Reaching the remotest communities and telling people: “these are your rights” Because people from rural areas don’t know healthcare is a right, meaning they have different rights. As well as the right to healthcare, they also have the right and the obligation to participate, they have to be agents for change in their communities, and in society at large. We have to awaken in them the desire to say: “I’m going to get involved, I’m going to participate, and I’m going to persevere with all those processes” and we’ve achieved that. There you have all the volunteers conducting oversight work. Awakening in them something that had been denied them for a long time or something they ignored, because the state also has the obligation to promote this but fails to do it. So we awaken the people and now people have become more active because they’ve seen positive results. We said: “If we were able to do this, we can achieve other improvements.” This is no longer focused on healthcare, it’s about education, it’s about children’s rights and women’s rights. Making a contribution to society gives us great satisfaction.

Paulina: My message to everyone is to recognize that healthcare is a human right. Because in the past we were not aware of this as [healthcare] defenders. So now I’d like everyone to know that healthcare is human right and it’s very important because the truth is there’s a lot of discrimination and mistreatment everywhere and people are given poor treatment. So I’d wish everyone to be aware of the fact that healthcare is a human right.



Paulina and Benilda arriving at the World Bank Group for the Global Partnership for Social Responsibility in November 2018. Paulina is carrying handicrafts on her head that she will offer for sale to participants.

Reflections for the Transparency, Participation and Accountability Field

- The identification and engagement of existing community leaders enabled a resilient network of volunteers with few financial resources to accomplish meaningful changes in Sololá.
- As the example of the hospital staff being allowed to wear traditional dress demonstrates, changes that may seem superficial to an outsider can have significant impacts on people’s access to services and wellbeing. This highlights the importance of democratic and inclusive processes for setting priorities for accountability work.
- Health defenders need different forms of support—from mentorship to legal support, depending on the challenges they face, and CEGSS is only able to meet these changing needs with the help of flexible funding.
- Good systems on paper require organizing, monitoring and capacity building to become effective. For example, the right to health in the Guatemalan Constitution is not being upheld by the state, but CEGSS and REDC-Salud’s strategic alliances and pressure campaigns are helping citizens to realize their rights. Also, health committees at different levels in Sololá were ineffective until pressure from organized social activists was applied to them in a critical yet constructive manner.
- Accountability in Guatemala is an uphill battle, but the successes described here show how informed and organized citizens can make meaningful changes, build powerful allies, and bring changes to society that are material, including ambulances and budgets, and non-material, including solidarity, accompaniment, increased respect.

Julia Fischer-Mackey – April 2020



Defenders from Sololá, at the REDC-Salud National Assembly. 2018.

Endnote

1. "Guatemala's legal framework created the Urban and Rural Development Council System (CDUR) in the year 2002 as a source of resources for social spending (...) The CDUR system has five tiers. The lowest tier includes the Community Development Councils (COCODE), which are based on community assemblies. Then, there's the municipal level and the Municipal Development Councils (COMUDE), which includes COCODE representatives, municipal government representatives, as well as representatives from other government bodies (such as the ministries of Health and Education) and non-governmental development organizations in the municipality (the municipal development council is different from the local government's municipal council). The COMUDE is led by the mayor. The next tier includes the Departmental Development Councils (CODEDE), which includes departmental authorities appointed by the Executive (ministries and secretariats), municipal authorities (the mayors of the municipalities in each department), the departmental governor. The most important of the five levels in terms of ascertaining social investment priorities is the municipal level, which is where the COCODE submits requests for infrastructure and social services. At this level, the COCODE and the municipal authorities discuss and agree on a final list that is submitted to the departmental tier in order to allocate the resources that will be distributed among the municipalities. The Development Council Act and its implementation is far from perfect and has many limitations, including the representatives' legitimacy, representation quotas within the councils and the process followed to allocate resources in order to meet different sectors' priorities." Flores and Gómez Sánchez (2010).

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