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GRASSROOTS VOICES



## Rural public health systems and accountability politics: insights from grassroots health rights defenders in Guatemala

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### ABSTRACT

As the pandemic reveals how multiple intersecting inequalities affect public health, the work of rural activists defending their communities' rights to health, land, and gender, ethnic and environmental justice demonstrate how intersectional analysis can be put into practice. In the interviews that follow, Guatemalan Maya Tz'utujil activists Paulina Culum and Benilda Batzin describe how 'health rights defenders' seek justice for rural indigenous communities – work that the pandemic makes more critical than ever. Their strategies and insights have implications for addressing rural health rights around the world.

### KEYWORDS

Health rights; defender; Guatemala; community health worker; accountability; COVID-19

## Preface: Framing struggles for rural health rights

Jonathan Fox

April 22, 2020 ¶

The world is rethinking what the right to health means in practice. Researchers are no exception, and the global pandemic is obliging us to think beyond our sectoral silos. Many rural activists have long been doing this, defending their communities on multiple fronts at the same time – including the fight for health rights along with their struggles for land, gender, ethnic and environmental justice. The *Journal of Peasant Studies*' 'Grassroots

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Editorial Note: The *Journal of Peasant Studies* is launching a rolling forum with experiences from the frontlines of the current crisis: 'Grassroots Voices: pandemics and critical agrarian studies' – in collaboration with the Transnational Institute (TNI - [www.tni.org](http://www.tni.org)). As the pandemic unfolds, many of the fatal flaws of capitalism are being laid bare. It is a moment when new alliances are being formed and new militant organizing is springing up, as are new forms of authoritarianism and repression. This is a moment of potentially great rupture – but in what direction and for who is up for grabs. The Grassroots Voices section seeks to document what is happening from the grassroots perspective. Migrant workers, domestic laborers, peasant farmers, small-scale fishers, informal food vendors, and rural-urban migrants all have had their lives upended. We expect this conjuncture to affect potentially radical changes in long-term trends towards authoritarian governance, industry consolidation, marginalization of migrant workers, land grabs and financialization, as well as creating a surge of left organizing, food worker strikes, mutual aid networks, and new grassroots alliances. What is the experience on the ground? These experiences of course are conditioned by the historical changes that came before, by rising populism, and the history of movement organizing. We hope to put these new experiences in historical context, track them longitudinally, and highlight emerging strategies.

Voices' section is well positioned to contribute, creating a space to listen and learn, in keeping with the journal's goal of 'special attention to questions of "agency" of marginalized groups in agrarian societies, particularly their autonomy and capacity to interpret – and change – their condition.' Health rights struggles are an arena of agency that has so far received little attention in agrarian studies.<sup>1</sup> The interviews that follow with Guatemalan Maya *Tz'utujil* activists Paulina Culum and Benilda Batzin shed light on how grassroots 'health rights defenders' put intersectional analysis into practice. They challenge social exclusion at one of the state's most significant interfaces in their communities: the public health system.

Just as the pandemic reveals multiple preexisting inequalities, analysis of health rights struggles sheds light on state-society relations more broadly. Like other public services, public health systems both produce and reproduce multiple, mutually reinforcing inequalities. Health systems have been studied primarily through a public health lens, rarely from a rural development perspective.<sup>2</sup> Conventional approaches to health system governance address accountability issues, but primarily through the lens of 'upwards accountability,' whereby frontline service providers report to managers, who in turn report to policy-makers, who report to elected officials, as well as to international donors and national financial sector technocrats who control the purse-strings. In contrast, the lens of 'downwards' accountability focuses on whether and how public service providers actually serve the public. Adding these adjectives to accountability is not mere academic parsing – the concept itself is so ambiguous and contested that effective communication requires specifying its inherently relational nature. Who is to be held accountable by whom? Is the term part of a bureaucratic audit culture, imposed from above, or is it a banner to be waved in democratic struggles against impunity and injustice, as movements call on public servants to serve the public? Accountability is a trans-ideological concept and is therefore both contested and up for grabs (Fox 2018).<sup>3</sup>

Accountability agendas in the public health field focus primarily on health workers, often to the exclusion of more systemic analyses of 'who gets what.' The pandemic is redefining the roles of health workers – an umbrella category that ranges from highly privileged professionals to low status paraprofessionals and volunteer community leaders. In contrast to these sharp, often gendered hierarchies, the shared threat of contagion has led 'health worker' to become a more inclusive collective identity. In contrast with classic frames as caregivers or functionaries, the identity of 'frontline workers' is also being socially (re)constructed and broadened.<sup>4</sup> Against the backdrop of social science research that has treated health workers as the target of audit cultures and top-down accountability

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<sup>1</sup>According to an online search of the entire collection of past issues of JPS, the term 'health' appears only once as a keyword and twice in a title.

<sup>2</sup>For example, there is a large, specialized public health literature on community health workers (often rural). A recent comprehensive review of that research found significant gaps in areas where other disciplines could contribute: 'on the rights and needs of CHWs, ... on CHWs as community change agents, and on the influence of health system decentralization, social accountability, and governance' (Scott et al. 2018).

<sup>3</sup>For a study of how grassroots rural movements in Mexico's state of Guerrero applied the discourse of transparency and accountability to their longstanding justice struggles, see Fox, Jiménez, and Haight (2009).

<sup>4</sup>Now that the term 'frontline' has been widely applied to health workers who risk their lives in order to carry out their mission, the term's military association recalls previous episodes in history when health workers have faced direct military threats – as in the case of Nicaragua in the 1980s, when civilian health workers in rural areas were targeted for assassination by the US government-backed Contra rebels. Their goal was to deprive the rural population of access to health services (Garfield, Freidman, and Verlund 1987, 615).

measures, researchers face a new imperative to understand how and why some health systems manage to inspire service providers with a sense of mission, while others do not.<sup>5</sup> Now, because of the pandemic, totally new arenas of rights struggles are also emerging, as health workers begin to fight for the right to protect themselves while doing their jobs, while their lack of protection is already leading to discrimination and stigma from those who may perceive them as contaminated threats. The shared interest between health workers and citizens in protecting health workers from contagion creates new coalitional possibilities.

Yet for experienced grassroots rights defenders like Paulina Culum and Benilda Batzin, whose struggle has been to exercise their legal right to oversee the state's interactions with indigenous communities, relationships with government health workers are complex and sometimes contested. On the one hand, health workers represent what little access to formal health care that most rural citizens have, working with the very limited public resources that the central government provides to clinics in indigenous territories. At the same time, doctors and nurses sometimes transmit hegemonic practices of racial, linguistic, gender and class discrimination, both to their patients and to lower status health workers. They may engage in charging illegal user fees and other abuses.<sup>6</sup>

This focus on health rights as a key state-society interface leads to the role of community health workers (CHWs), who play a bridging role between state and society.<sup>7</sup> They are expected to both represent the state to society, as cogs in the system, while also (sometimes) representing their communities to the state (Schaaf, M. et al. 2018a, 2018b, 2020). This frontline role is often referred to as the 'last mile,' a term that implies a view from above, from centers of power and decision-making. In contrast, seen from the community level, these paraprofessional outreach workers are the *first mile*, in term of accessing the state (Boydell, Fox, and Shaw 2017).

The community health worker tradition goes back to the 1930s and was famously expanded in Maoist China as 'barefoot doctors.' Promoted by the watershed 1978 Alma Ata global health summit, many countries have long deployed vast armies of these community paraprofessionals (e.g. Bangladesh, Brazil, Ethiopia, India, Malawi, Mexico, Myanmar, Nepal, Pakistan, Rwanda, Thailand, South Africa, among others). CHWs are likely to be called upon to help to address the pandemic.

In some countries, CHWs are organized into large unions, which are needed to defend both community health rights and their own rights as workers (e.g. Brazil, India, Pakistan).

<sup>5</sup>Contrast two emblematic studies. Banerjee et al detail an Indian case of nurses' resistance to a field experiment that attempted to impose top-down surveillance mechanisms without addressing the nurses' motivations (2008). In contrast, Tendler and Freedheim's institutional political economy analysis identified how in a Brazilian public health program: 'The state created an unusual sense of "calling" among the program's workers, a sense of prestige in the communities where they worked, and an informed citizenry that both monitored the workers and trusted them' (1994, 1771).

<sup>6</sup>For a recent review of the literature on 'informal payments,' see Schaaf and Topp (2019). On anti-corruption issues in health systems more generally, see Vian (2020). Accountability frames can also address systemic injustices that are independent of corruption, such as anti-rural bias in public resource allocation or lack of interpreting services for access to health services in vernacular languages. In contrast, the development industry's approach to accountability emphasizes rural health worker 'performance' in terms of fulfilling tasks, usually without addressing whether or not governments respect their labor rights, provide training and equipment, or actually pay their salaries. For example, in the predominantly rural, Afrodescendant Colombian province of Chocó, the government owed health workers vast sums of back pay well before the Covid-19 crisis. <https://www.elspectador.com/noticias/nacional/personal-del-hospital-de-tado-choco-denuncia-falta-de-pagos-y-deterioro-de-la-infraestructura-articulo-913702>

<sup>7</sup>On state-society interfaces, see Long (2001) and Hevia and Isunza Vera (2010).

India's National Rural Health Mission, launched in 2005, dramatically increased the size of the government's CHW program and they are unionized in several states.<sup>8</sup> Notable Indian CHW innovations include the Mitandin program in the state of Chhattisgarh, where a semi-autonomous government agency recruits, trains and supports nearly 70,000 CHWs with a community organizing ethos, working mainly with women from indigenous and Dalit backgrounds through a train-the-trainer approach (Garg and Pande 2018; Nabiar and Sheikh 2016). CHWs often serve their own and/or neighboring communities and speak multiple languages, enabling them to build trust and effectively communicate essential health information. Governmental respect for CHWs as community voices can help to address the lack of trust between citizens and health authorities that has impeded public health measures in epidemics such as Ebola (e.g. Yamanis, Nolan, and Shepler 2016).

Many governments also promote community health committees that nominally play an oversight or co-management role for rural clinics and health posts. Though these local committees often exist only on paper, some governments have experimented with large-scale efforts to activate them to bolster citizen oversight, most notably in India.<sup>9</sup>

A different strategy to encourage public health systems to become more responsive to rural communities relies on networks of completely non-governmental citizen monitors, such as the defenders profiled here. Public health practitioners have joined with grassroots leaders to experiment with these independent community-based health system oversight strategies.<sup>10</sup> The testimonies from Paulina Culum and Benilda Batzin are emblematic of these rural health rights struggles. They represent the Network of Community Health Rights Defenders (REDC-Salud) and the Center for the Study of Health System Equity and Governance (CEGSS), organizations that are committed to an especially strategic, power-shifting approach in the emerging field of 'accountability work.' Their approach to building public accountability into state-society relations is distinctive in at least eight ways.

First, their grassroots health rights struggle invented a public collective identity of 'defender,' grounded in elected, organic community leadership and gender equity.<sup>11</sup> The defenders wear their politically constructed identity proudly, with the term emblazoned on the backs of their distinctive work vests in its gender-neutral form – *Defensor(a)*. Their mission includes educating their own and neighboring communities about their rights, interviewing people at clinics to document possible abuses and seek recourse, while broadcasting rights messages on community radio in Mayan languages that appropriate claims drawn from national laws that would otherwise just gather dust.

<sup>8</sup>Scott, George, and Ved (2019) review the vast literature and find a need for more 'critical comparative research ... [to] ... feed back into programme reforms ... , particularly related to governance, intersectoral linkages, ASHA solidarity, and community capacity to provide support and oversight.'

<sup>9</sup>For example, India's National Rural Health Mission supports the Community-Based Monitoring and Planning program in rural Maharashtra. See the work of Support for Advocacy and Training to Health Initiatives (SATHI) at <http://sathicehat.org/>. Like CEGSS, they have produced an extensive body of reflective action-research and evaluation. See Khanna (2013); Marathe et al. (2020); Shukla, Scott, and Kakde (2011); Shukla and Saha (2014); and Shukla, Saha, and Jadhav (2015).

<sup>10</sup>Drawing from these diverse experiences with using accountability discourse to claim health rights, from both the state and society, the international global South-led Community of Practitioners on Accountability and Social Action in Health (COPASAH) promotes mutual learning and exchanges of experiences. See position papers and grounded case studies at <https://www.copasah.net/>.

<sup>11</sup>The term 'collective identity' registers (only) 46 times in the entire online collection of the *Journal of Peasant Studies*, which suggests that more direct engagement with the political sociology literature on social movements would be productive. See, for example, Van Doorn, Prins, and Welchen (2013).

Second, in the world of civil-society-building, the alliance between CEGSS and REDC has constructed a balanced CSO-grassroots movement relationship – always easier said than done. While CEGSS emerged from the field of public health, it has more recently transitioned to take on a broader democratic reform agenda. The network of volunteer indigenous defenders recruits experienced community leaders, many with long track records of campaigning for indigenous women’s rights, grassroots development or against toxic mining.

Third, CEGSS and the Network of Defenders are committed to evidence-based advocacy and problem-solving. In their early years they followed a mainstream public health approach to evidence, yet they found that local authorities were unimpressed by well-organized quantitative data. Over time they diversified their evidence-gathering approach, emphasizing tools that grassroots leaders could take on, such as audio and visual testimonies – which proved to be harder to ignore (Flores 2018).

Fourth, in contrast to many of the approaches to citizen engagement and social accountability promoted by the development industry and national governments around the world, these organizers are building *countervailing power*. This concept focuses on actors with the capacity to push back against concentrations of elite power, both in state and society. Though this idea is key to understanding what makes public accountability possible – it is largely missing from the ‘light touch’ field experiments that dominate mainstream social science research in the emerging field of transparency and accountability (Fox 2015). As Fung and Wright put it, countervailing power refers to ‘a variety of mechanisms that reduce, and perhaps even neutralize the power advantages of ordinarily powerful actors’ (2003, 260). Countervailing power involves bargaining power – the leverage needed both to question authority without reprisals – and to get those in power to listen. Countervailing power can be expressed in either adversarial or collaborative terms, but it is constituted by actors or institutions with some capacity to tangibly push back and constrain the abuse of power.<sup>12</sup>

Fifth, together with CEGSS, the defenders connect their local oversight work with provincial and national level problem-solving and policy advocacy, transcending conventional localistic approaches. In contrast to mainstream approaches to social accountability that address symptoms rather than underlying, systemic causes of social exclusion, this alliance pursues multi-level independent policy monitoring and advocacy. They combine problem-solving in response to felt community needs (like missing ambulances) with ‘upstream’ efforts to promote more inclusionary national policies, such as socially responsible health budgets and anti-corruption efforts. This multi-level strategy is also known as ‘vertical integration,’ a term that draws on the political economy metaphor in an effort to capture the idea of trying to coordinate efforts to monitor and influence each link in the chain of decision-making of powerful actors, from global and national to local.<sup>13</sup>

Sixth, their approach bridges a ‘speak truth to power’ social accountability strategy with the legal empowerment approach. Legal empowerment has been pursued extensively around the world, across issue areas – though primarily in the countryside, and with

<sup>12</sup>This paragraph draws on Fox (2020). For CEGSS approaches to power analysis, see Flores (2019), Flores and Ruano (2015) and Hernández et al. (2019).

<sup>13</sup>See Fox and Acheron (2016) and Fox (2016). For an innovative application of this multi-level analytical framework to an agrarian reform campaign in the Philippine province of Bondoc, see Isaac, Carranza, and Acheron (2017). Acheron extends this approach in a comprehensive comparison of six multi-level advocacy campaigns (2018).

special attention to land rights. Legal empowerment approaches have many moving parts, but the core involves training and deploying community paralegals to help to ‘squeeze bits of justice out of unjust systems’ (Feinglass, Gomes, and Maru 2016; Joshi 2017; Maru and Gauri 2018).

Seventh, the Guatemalan strategy profiled here transcends the conventional dichotomy between adversarial and collaborative approaches to engaging with the state. Where the defenders identify rights violations or corruption, they use their socially grounded advocacy tools and legal complaints to push back. At the same time, they seek to work with government counterparts who are respectful and responsive, leading to partnerships with mayors, municipal development councils, health system administrators and the government’s Human Rights Ombuds office.<sup>14</sup> In more theoretical terms, their action repertoire transcends a two-dimensional view of collaborative vs. adversarial approaches, illustrating instead a three-dimensional approach to state-society relations that has space for *simultaneous* collaboration and confrontation (Fox 2016). They target different elements within the state depending on where the pro and anti-accountability forces are located.

Eighth, Paulina Culum and Benilda Batzin represent reflective learning organizations that put democratic principles into practice, inspired by a Latin American legacy of popular education that lives on in the region’s social movements – in spite of the ebbs and flows of national politics. Their commitment to learning includes a sustained emphasis on action-research that has informed both their own strategy and the work of counterparts around the world, including efforts to introduce more pluralistic approaches to evidence to the field of public health (Flores 2018).

The testimonies that follow spotlight the analyses of ‘action-strategists.’ The Accountability Research Center works with this new term to describe activists and other practitioners in a way that recognizes that they are knowledge producers, with analytical insights that inform action – and should also inform research agendas. To sum up, the CEGSS and REDC experience illustrates numerous cutting-edge issues involved with rural health rights struggles more generally. Yet it is their *combination* of these distinctive characteristics that makes their experience so important to listen to.

This Grassroots Voices section’s focus on learning from rural health rights struggles and the role of agency points to both strengths and limitations of critical development studies approaches to these issues. The critical development studies literature that addresses health focuses primarily on state vs. market-led regimes, the drivers of inequality, the influence of international agenda-setting and concern for neoliberal co-optation of elements of progressive public health agendas.<sup>15</sup> This focus is reflected in the diverse analyses convened by O’Laughlin (2016). She concludes, however, that those approaches ‘offered more in critique than in providing an alternative transformative vision of how to reclaim politically the space of reform’ (O’Laughlin 2016, 705). Indeed, the critical

<sup>14</sup>For a comparative analysis that distinguishes between different terms of engagement with municipal health authorities in Guatemala, see Hernández et al. (2019). Another social accountability initiative in Peru sustained a partnership between grassroots indigenous women health rights defenders, a national health rights CSO coalition and the Puno regional office of the national human rights Ombuds agency – also affiliated with the COPASAH network (Frisancho and Vásquez 2015; Samuel 2016). This official legitimacy for watchdog work bolstered the standing and room for maneuver for independent oversight.

<sup>15</sup>This line of work is especially timely insofar as privatization has undermined investment in preventative public health. ‘Compromised health systems’ clearly produced vulnerability to previous pandemics (Wilkinson and Leach 2015).



development studies literature could do more to address the actors, movements, campaigns and strategies involved in health rights struggles – as well as their research needs. It is especially relevant to identify where key decisions in health systems are made, which can help to distinguish between the symptoms and the causes of inadequate service provision.<sup>16</sup> Relevant research strategies include institutional ethnography and follow-the-money political economy analysis, to identify who gets what – and who decides – with greater precision. Specifically, problem-driven research agendas can help to inform change strategies by disentangling the inter-related but distinct problems of corruption, systemic social bias and exclusion, administrative dysfunction, and insufficient public funding – as well as by distinguishing between the responsibilities of local, national and international health system actors. To sum up, from the point of view of accountability politics, one of the practical research challenges for rural health rights advocates involves how to open up the black box of the system to identify the underlying causes of failures with greater precision.

To come back to the relevance of this Grassroots Voices section of JPS to the global pandemic and economic crisis, it is far from clear how these twin shocks will affect rural peoples in the global South. State capacity and social safety nets are being put to the test all over the world. While regimes with authoritarian inclinations reach for more power, social movements are feeling out their new constraints. After a decade of ebbs and flows of movement efforts to seek synergy between online and face-to-face organizing all over the world, rural organizers now have little choice other than to experiment with digital repertoires, from low-bandwidth WhatsApp to new hashtags like Via Campesina's #StayHomeButNotSilent.

We are in a new age of coming together while staying apart, which challenges our creativity to invent and refine new forms of dialog between activists and researchers. Yet such dialog is needed now more than ever, to address the forced isolation of rural communities and the socially excluded who are not online, to raise awareness of their specific vulnerabilities, and to inform possible change strategies. Frontline rural health rights activists are especially well-positioned to anticipate and report potential gaps or negative effects of government policies to address the pandemic.<sup>17</sup> This critical juncture creates both new threats and new opportunities for rural rights defenders. New actors, coalitions and repertoires may emerge, while longstanding actions and approaches will be put to the test.

These unfolding trends raise three broad sets of questions for agrarian studies as a field. First, how can more synergy be created between public health research and critical agrarian studies?<sup>18</sup> Reviews of the vast public health literature consistently find that more power analysis is needed (e.g. Scott et al. 2018; Scott, George, and Ved 2019) – and here agrarian studies has great strengths. Second, how can analysis of rural health rights struggles shed light on broader questions of accountability politics – and vice versa? The field of agrarian studies could address the dynamics of power-shifting at the

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<sup>16</sup>For example, frontline health workers may not show up for work, or they may charge patients 'informal payments,' but the underlying causes may be systemic (such as non-payment of wages, or the extraction of bribes by managers) rather than purely the result of individual failings (as is often assumed by social science field experiments – e.g., Banerjee, Glennerster, and Duflo 2008). See Schaaf and Topp (2019).

<sup>17</sup>Thanks to Walter Flores for sharing this observation.

<sup>18</sup>For example, see the STEPS Centre's interdisciplinary work on epidemics and pandemics (<https://steps-centre.org/covid-19-coronavirus-resources-research-epidemics-pandemics/>).



state-society interface more explicitly. Third, how will the global nature of the pandemic influence our 'ways of seeing?' Will new ideas about rights and collective identities change the landscape of coalitional possibilities? We are already seeing this with the expansion of 'frontline workers' to include those who risk their own lives to protect others. This is what so many agrarian rights activists have long been doing, all over the world – risking their lives as frontline workers for justice.

## Reflections of two indigenous women defending the right to health in Guatemala

### *Introduction*

Julia Fischer-Mackey

April 24, 2020 ¶

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 rights 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.

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 has 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. The interviews with Paulina and Benilda were conducted jointly to understand how they think about their work, what motivates them, what strategies they use to build partnerships with community leaders and powerful government agencies, and how their identities as Tz'utujil women influence their experiences and perspectives.

These interviews were conducted in 2018 – long before the current COVID-19 pandemic upended global and local economies and health systems. However, Benilda and Paulina’s insights are extremely pertinent to current policy debates and social movements about equity in health services and accountability of health systems.

First, the COVID-19 pandemic is having disproportionate impacts on marginalized communities because of underlying health disparities and differential access to care. Meanwhile, both the public and private sectors’ responses to the pandemic have disproportionately attended to the needs of the urban, wealthy, and politically powerful. Civil society organizations and grassroots community leaders such as those featured in this paper have decades of experience accompanying, organizing, and conducting strategic advocacy to address the interaction of exclusionary structures and social bias that results in poor service provision for women, the poor, and racial and ethno-linguistic minorities. Their experience, skills and knowledge will enable them to advocate effectively for policies and practices that better serve marginalized communities during and after this crisis.

A second, equally important contribution of these interviews to our thinking about the current crisis is that right now, there is a tendency in hard-hit countries to valorize healthcare workers – with good reason, as they are risking their lives to save others. However, in rural Guatemala, many government healthcare workers are not members of the indigenous communities they serve, and there is a history of health staff being unaccountable to, and disrespectful towards, indigenous clients. Patterns of discrimination and abuse that have been documented in Guatemala (see [Box 1](#)) may only become worse with the crisis. Given this history, accountability efforts and community organizing designed to protect indigenous communities’ rights and ensure that they receive the health services that the Constitution guarantees them is more important than ever.

**Box 1. 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.’

Paulina and Benilda recently provided a brief update to explain their activities since the COVID-19 crisis began. Paulina describes her work in the following way:

With municipal authorities, the first thing we did was to inform the population about what the coronavirus is, how to prevent it and where a person with symptoms should go. We are also working on the [health] promotion, [information] dissemination and organization of the population within the municipality so that the measures decreed by the Government of Guatemala

do not [negatively] affect the vulnerable population because the information has not reached them. Furthermore, we are informing citizens of the importance of staying home. The state of emergency, quarantine and curfew are some of the orders established by the Government of Guatemala. We are jointly monitoring, with the Council of Elders and local governments, so that there is no abuse of authority or violation of the human rights by the National Civil Police and the army.

The basic food basket has been increased, so we coordinate with the local authorities to take some measures and visit the merchants, notifying them of the legal requirement that they not raise the prices of the products. The local governments are helping to provide basic foodstuffs (corn, sugar, salt and noodles) to low-income families.

From everything we have learned in the trainings and workshops on our rights – the experience of knowing my rights as a person, also but as a woman, has helped me a lot, because I can demand and present proposals to the authorities for the fulfillment of their responsibilities. Especially now in the state of emergency, where different problems are emerging, and the needs of the population are different.

In the case of [returning] migrants, we have raised awareness, coordinated and worked with families so that they report the arrival of their relatives, with the aim of not affecting the population [by spreading the virus]. I am also serving as an intermediary between the authorities and families.

Benilda describes her work as follows:

Since the beginning of the COVID-19 crisis, I have been advising and guiding defenders by phone; providing information on COVID-19 and what to do if a case arises. In my town I'm monitoring the development of this health crisis and how it is affecting indigenous communities, vulnerable and isolated populations in Guatemala and documenting this on a weekly basis on a digital platform. I collect this information by interviewing health defenders in different communities. I am also following up on the cases of human rights violations that the government is committing against these communities.

It is necessary to highlight that the information that is being documented and followed up on in the communities has to do with access to health services, availability of transportation, availability of food, speculation and hoarding, [and] compliance with government orders and compulsory use of masks. I then produce a report with conclusions and recommendations for publication and demand that the authorities of government implement actions and solutions to the problems.

The experience working with REDC-Salud has allowed me to develop new knowledge, skills and capacities that right now serve to support communities in my municipality. In the face of this health crisis, I am advising on mediation, [health] promotion, coordination with local authorities, as well as patient support, problem solving and supporting the work of defending the right to health. This has been facilitated because the defenders and I have done capacity building in citizen empowerment, defense of rights, negotiation and accompaniment of cases of violation of the right to health.

Benilda and Paulina's flexibility and resourcefulness enable them to adopt new tactics to address new threats, from increased hunger due to the lockdown, to risks of exploitation by merchants and security forces, to intra-household conflict related to returning migrants who are feared to be carrying the virus. The women are able to navigate this new reality effectively because they have built trust with communities through their collaborative and inclusive approach to recruiting defenders and organizing actions. These bonds of trust, along with their fluency in multiple Mayan languages, may help the

defenders play an important role in disseminating critical health information which community members would not otherwise receive.

In the following interview excerpts, Paulina and Benilda describe how they acquired these leadership and organizing skills and how they have approached their work in a way that has led not only to concrete gains in making the health system more accountable but also to a resilient network of health rights defenders who are playing a critical role in protecting citizens' rights in the current crisis. Without the many years of developing leadership skills and building networks of allies, which are described below, the current work would not be possible. The defenders still face deep structural challenges that require allies and sustained support. The interviews highlight these leaders' perspectives and strategies to make health systems work for rural indigenous populations in Guatemala.

***A community leader with a deep personal commitment to justice builds respect and influence over time***

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 Tz'utujil Women's Organization (Organización de Mujeres Tz'utujiles), as we were located in the basin of the lake but in the Tz'utujil area ...

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 Weaving Forces for a Good Life (Tejiendo Fuerzas para el Buen Vivir), 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 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.

***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 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 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) [To understand the risks faced by defenders, see [Box 2](#).]

## **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.

- 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 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 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.<sup>19</sup> 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

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<sup>19</sup>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.' From Flores and Sánchez (2010).



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 dialog. 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.'

### ***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 Maya 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, healthcare 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 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, fieldwork, 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 Patzuxtún, 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.

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. It was a process that took months and at that 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.' 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 the first medium-term achievement (Figure 1).

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 Procuraduría 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 Procuraduría'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: Alliances are also being built now and they have been strengthened thanks to the Human Rights Ombuds' Office (PDH). Establishing exchanges with the PDH in Sololá was also a brainchild of the REDC network. We're working on this 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.

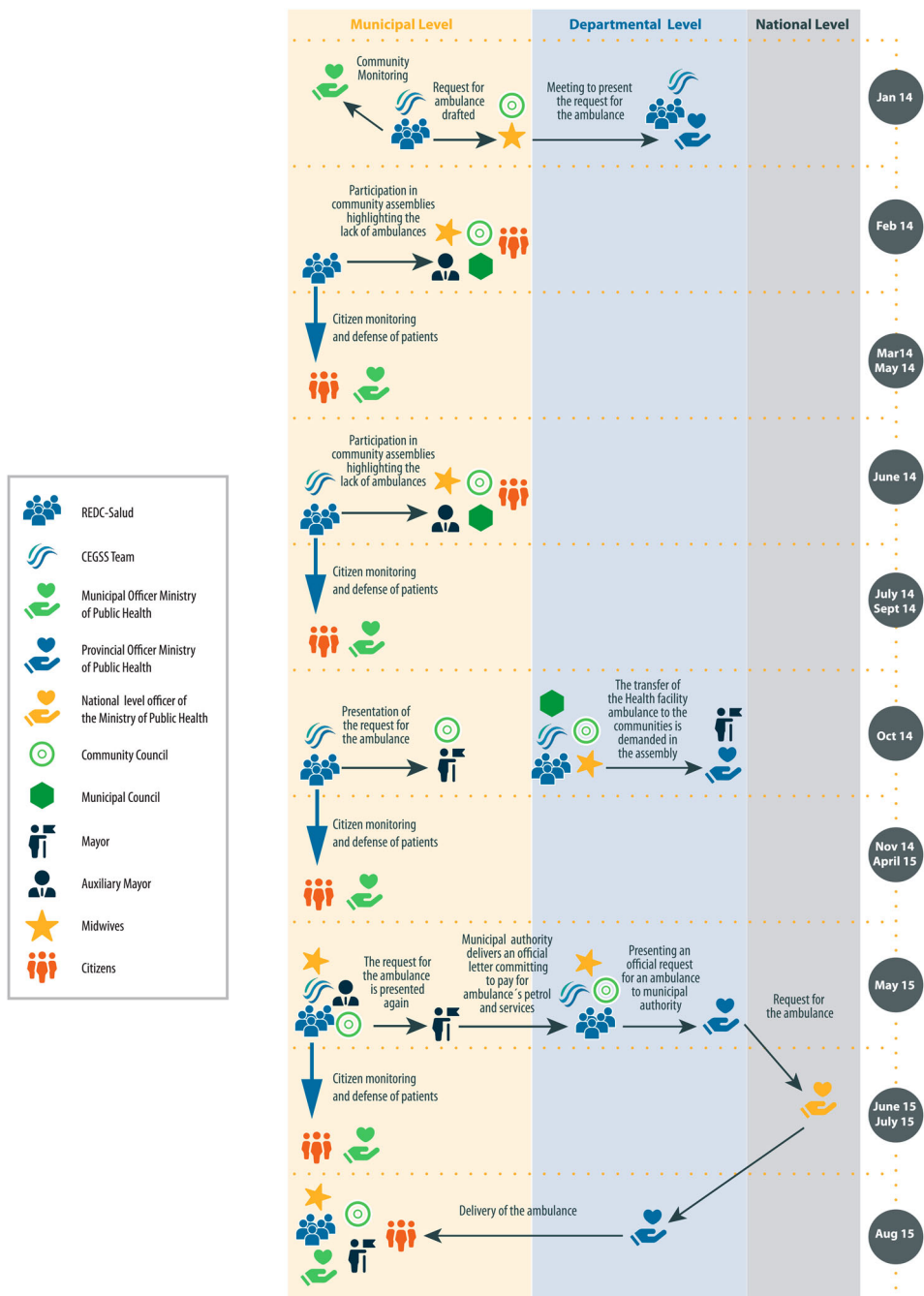
The REDC-Salud network presented its work [to the Ombuds' office], how it was done, the methodology used because they monitor public services. They're the ones monitoring public services. As a result, we managed to get the PDH to look into the emergency transportation issue in Sololá's 19 municipalities.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

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 coordinates its work [with the PDH], it has a strong alliance with the PDH.

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.



**Figure 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.

- 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 CEGSS, exercise oversight at a more local level. That's where we've identified most cases of 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 grass-roots. 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.

## **Final Thoughts**

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 health rights is a human right. Because in the past we were not aware of this as [health rights] 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.

Julia: As I listened to Benilda and Paulina speak about their lives, I noted shared characteristics and tendencies that I think contribute to their extraordinary leadership abilities and accomplishments. The first is that they build on their innate strengths and take every available opportunity for personal and professional growth. As a child, Paulina's integrity and bravery were recognized by her peers, who gave her the initial opportunity to speak on their behalf in a workshop. She took that opportunity, but she did not stop when the workshop was over. Instead, she took what she learned and co-founded a women's organization, because none existed in her region. When CEGSS was looking for a new executive director, Benilda did not shy away from the opportunity. When she was elected, she took on leadership of the national organization, but also continued to provide accompaniment and support to defenders in Sololá. The confidence, commitment, energy that they demonstrate is inspiring.

The second tendency that Paulina and Benilda share is that when action is needed, but there are barriers, they forge a path of their own. As Paulina was becoming a community leader, she faced resistance from her community against female leaders. This did not deter her, and she is now building a legacy of female leaders by mentoring younger women. When the Human Rights Ombuds' Office at the national level was slow to partner with CEGSS, Benilda built a relationship with the Ombuds' office at the departmental level. This persistence and boldness in the face of resistance has led to outcomes that few would have thought possible.

The third shared characteristic is their pride in their identities as indigenous Maya Tz'utujil women. They refuse to see their identities as a liability, as existing norms and power structures do, but claim it as an asset that gives them insight into how power operates and why rights need defending. Through their inclusive processes to identify problems and solutions, Benilda and the defenders in Sololá realized that if health staff wore identification cards and traditional dress, indigenous citizens needing translation would have an easier time identifying someone who could help them. Traditional dress, which is worn more by indigenous women than men in Guatemala, may have been overlooked as an important issue by a conventional civil society organization without strong ties to the lived experiences of rural indigenous people. By being attuned to the needs of minority language speakers and how women (and men) identify and connect with others when they need translation assistance, Benilda and her colleagues understood the importance of this issue. This value of indigenous cultures, and of women's expression of those cultures, became a political act – by calling for staff to be permitted to wear traditional dress, they explicitly reject the idea that traditional dress and professionalism are incompatible.

Finally, what I see as remarkable about these leaders is that by adopting and adapting the language of human rights to claim their power and frame their objectives, Benilda and Paulina have been able to unify individuals across social, linguistic and geographic distances to develop a collective identity as health rights defender. This identity is flexible and adaptable, and does not preclude other roles that the defenders play in their communities. Their focus on

human rights allows them to apply their skills to various problems as they emerge – from food price inflation, to security services abuses – and their roles will surely evolve along with the current crisis.

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No potential conflict of interest was reported by the author(s).

## A Note about this Manuscript

The body of this article was developed to produce an *Accountability Note* published with photos, in English and Spanish, by the Accountability Research Center (<https://accountabilityresearch.org/publication/defending-the-right-to-health-in-guatemala-reflections-of-two-indigenous-women-on-the-frontlines/>.) Julia Fischer-Mackey conducted open-ended interviews in Spanish with Benilda Batzin and Paulina Culum to understand their life experiences and current work. Julia reviewed the translated transcripts to identify themes, which she used to select excerpts. She then she wrote framing questions and an introduction. Additional academic and organizational materials were provided by CEGSS to explain particular issues. The preface was written by Jonathan Fox specifically for the Grassroots Voices section. The updates about the COVID-19-related activities were provided by Benilda and Paulina.

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**Center for the Study of Equity and Governance in Health Systems** (Centro de Estudios para Equidad y Gobernanza en los Sistemas de Salud, 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 science. The CEGSS team is made up of 14 staff members, more than half of whom are women and/or indigenous. <https://cegss.org.gt/en/>

**Network of Community Defenders of the Right to Health** (Red de Defensores y Defensoras Comunitarios por el Derecho a la Salud, 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. <https://vigilanciaysalud.org/>

**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. [www.accountabilityresearch.org](http://www.accountabilityresearch.org)

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