

Building Trust through Lymphatic Filariasis Elimination: A Platform to Address Social Exclusion and Human Rights in the Dominican Republic

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Abstract

Hispaniola, the Caribbean island that includes the countries of Haiti and the Dominican Republic (DR), accounts for 90% of lymphatic filariasis (LF) in the Americas. Both countries have committed to LF elimination by 2020. In the DR, LF occurs mainly in *bateyes*, or company towns that historically hosted migrant laborers from Haiti. A legacy of anti-Haitian discrimination as well as the 2013 *Sentencia*, which stripped generations of Haitian-descended Dominicans of their citizenship, ensure that this population remains legally, economically, and socially marginalized. Despite this context, the country's LF elimination program (PELF) has worked in *bateyes* to eliminate LF through health education and annual drug treatment to interrupt parasite transmission. Based on interviews with *batey* residents and observations of PELF activities from February–April 2016, this study describes local understandings of social exclusion alongside the PELF community-based approach. The *Sentencia* reinforced a common perception shared by *batey* residents: that their lives were unimportant, even unrecognized, in Dominican society. At the same time, the government-run PELF has generated trust in government health activities and partially counteracts some of the effects of social exclusion. These findings suggest that neglected tropical disease (NTD) programs can not only improve the health of marginalized populations, but also create a platform for improving human rights.

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Introduction

In the Western hemisphere, the story of lymphatic filariasis (LF)—or rather, the story of people who live with LF—begins with an ignoble chapter in human history.¹ Along with untold millions of enslaved Africans, the Atlantic slave trade brought the disease from Africa to the Caribbean island of Hispaniola.² The first site of European conquest in the so-called New World witnessed the decimation of an indigenous population and a plantation system so ruthless that it was cheaper to import new slaves and let the sick or injured die.³ Haiti arose out of this colonial furnace as the first free black republic in the world. The Haitian Revolution (1791–1804) was so radical that, at the time, “not even the most extreme political left in France or England had a conceptual frame of reference” for what happened there: that African slaves would overthrow their masters, defeat a colonial army, and yearn for the same Enlightenment rights as white Europeans.⁴ On Hispaniola, then, the long and conjoined relationship between human rights and this neglected tropical disease (NTD) goes deep.

LF is a mosquito-borne, parasitic disease with social and economic costs estimated at 2.8 million disability-adjusted life years (DALYs) globally.⁵ LF is endemic in 72 countries, with 856 million people at risk for infection and 40 million currently suffering from the disfiguring and disabling complications of lymphedema or hydrocele.⁶ The World Health Organization (WHO) targets elimination of LF as a public health problem through annual mass drug administration (MDA) to interrupt parasite transmission and provision of morbidity management and disability prevention (MMDP) services to alleviate suffering for those already affected.

At present, Hispaniola accounts for 90% of LF in the Americas.⁷ Haiti, the poorest country in the hemisphere, bears a higher disease burden than the DR.⁸ Haiti’s poverty has largely driven labor migration to the DR. Over time, Haitian migrants have gradually replaced ethnic Dominicans and other immigrant groups on Dominican sugar plantations, living in adjacent company settlement villages called *bateyes*. In 2016, Haitian-born migrants were estimated to comprise 23.2% of the nationwide

batey population.⁹ LF is rare outside of *bateyes*, meaning that they have been the predominant foci of LF transmission, likely due to the regular influx of Haitian migrants that may inadvertently import infection from Haiti, combined with impoverished environmental and sanitary conditions that favor breeding of the *Culex* mosquito vector.¹⁰

The DR is distinct among Caribbean nations because it was there that large-scale sugar plantations expanded *after* the abolition of slavery.¹¹ Through the early 20th century, Haitian migrants were crucial to the growth of sugar production yet also were cast as a threat to Dominican society. The dictator Rafael Trujillo (1930–1961) manipulated colonial-era sentiments of race both to exploit the migrant workforce and to consolidate power over a bicultural and largely harmonious world made by Dominican and Haitian peasants.¹² It is unclear to what extent *anti-haitianismo* (anti-Haitianism) exists as popular ideology in the DR today. More likely, it continues to be a useful tool for the Dominican elites to justify their economic power.¹³ Indeed, the ideology has generally served those wielding greatest power throughout the history of the DR: early colonial rulers; the intelligentsia of the newly formed republic; North American corporate enterprises and the American military; and certain contemporary Dominican political parties and policymakers.¹⁴

In addition to migrants from Haiti, *bateyes* are also home to Dominican-born persons of Haitian descent, who comprised an estimated 25.5% of the total *batey* population in 2016.¹⁵ Like migrants, they too contend with a history of discrimination in the country. The 2013 Constitutional *Sentencia*, or “the Sentence,” which stripped citizenship from an estimated 200,000 people of mostly Haitian descent, further reinforced their marginalized status.¹⁶ This decision reinterpreted the principle of birthright citizenship—in effect since 1929—by arguing that children born to those in an irregular migratory situation were “foreigners in transit” and not entitled to Dominican citizenship. Revoking citizenship has left them unable to perform basic civil functions such as registering children at birth, getting health insurance, enrolling in school and

university, participating in the formal economy, presenting legal claims in courts, or traveling within the country without risk of expulsion.¹⁷

These downstream effects point to how the 2013 *Sentencia* violates fundamental human rights already enshrined in Dominican law. For example, the Dominican Constitution contains articles on the rights to health (Art. 61) and equality (Art. 39) while the Criminal Code penalizes discrimination based on origin or race, among other distinctions (Art. 336).¹⁸ Furthermore, the country has ratified multiple international frameworks pertaining to discrimination, including the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Just five months before the *Sentencia* verdict, an ICERD country report for the DR expressed concern over legislative and judicial hurdles that block access to identity documents for dark-skinned people and the Haitian irregular migrant population.¹⁹

The far-reaching consequences of statelessness on human rights should be quoted in full. The 2015 report released by the Inter-American Commission on Human Rights (IACHR) states that loss of nationality has increased vulnerability to other rights violations, including:

*the right to personal integrity, the right to the protection of their honor, dignity, and private life, the right to protection of the family and family life, the rights of the child, the right to education, the right to health, the right to work, the right to private property, the right to due process of law, the right to judicial protection, political rights, the right to movement and residence, as well as the right not to be arbitrarily deprived of their liberty, the right not to be expelled from the territory of which they are nationals or the right to enter in said territory, the prohibition of collective expulsions, among others.*²⁰

In short, social exclusion in the DR creates exceptions to what the country would otherwise claim as universal rights.

There is, however, some alignment between policy and practice from the standpoint of the right to health. The Dominican Constitution declares that *toda persona*—every person—has the right to “integral health” and calls for the state to “procure

means for the prevention and treatment of all sicknesses, ensuring access to quality medication and giving medical and hospital assistance for free to those who need it.”²¹ The Dominican Ministry of Health has operationalized this lofty goal in part by establishing government-funded primary care centers in or near *bateyes*. Each is staffed by a doctor, nurse, supervisor, and several community health promoters.²²

In 1998, the Dominican Ministry of Health established the *Programa de Eliminación de la Filariasis Linfática* (PELF). Baseline mapping revealed LF infections among the *bateyes* in the southwest and east of the country, along with a small focus in an impoverished neighborhood of Santo Domingo (*La Ciénaga*). Due to funding limitations, PELF began interventions only in the most endemic region (southwest) in 2002, but gradually scaled up to each of the three foci. The main intervention is annual house-to-house MDA of albendazole (donated by GlaxoSmithKline) and diethylcarbamazine (donated by Eisai since 2013) in target communities.

Initially, PELF was a vertical program in which strategy, evaluation, and interventions were centrally directed. However, the program rapidly recognized the importance of community engagement to achieve sufficient MDA coverage—at least 65% of the total population in endemic areas.²³ Beginning in 2003, interventions were folded into the local health care system.²⁴ By mobilizing local primary care staff, neighborhood associations, and community volunteers, MDA campaigns have avoided a separate operational structure, helped to generate trust and job satisfaction, and improved MDA coverage.²⁵ Average population coverage has been 80.7% across all MDA campaigns. To date, LF antigen prevalence in the southwest and *La Ciénaga* has been reduced to less than 2%—the level at which MDA is no longer needed.²⁶ In the east, stop-MDA transmission assessment surveys are planned in 2018.

These accomplishments are especially noteworthy because the chronology of PELF and its MDA activities correspond to a period over which the Dominican political and judicial system took a more aggressive stance towards the migrant and

Haitian-descended population.²⁷ For example, in 2004, the Dominican legislature passed the Immigration Act, which adopted stricter nationality criteria; in 2007, administrative procedures were introduced to suspend or retain birth certificates to those born to parents without Dominican residency; in 2011, a regulation added more requirements, many of which were nearly impossible to fulfill, to acquire legal status; and in 2013, the Constitutional Court issued the *Sentencia*.²⁸ These legislative and judicial steps, coupled with the impoverished living conditions found in *bateyes*, have helped to create “a tragic cycle in which a future of poverty is almost inescapable.”²⁹

How, then, to account for the successful public health campaign to eliminate LF in *bateyes* amid a context of social and legal exclusion? This paper responds to this question from two angles: by exploring social exclusion in *bateyes*; and by describing the community-directed approach of the PELF program. Here, *social exclusion* focuses on subjective experience, or how people perceive certain relations, events, or circumstances that signal their rejection or not mattering in a local world. The analysis of PELF gives attention to community engagement processes between PELF and the *bateyes*. Examining social exclusion alongside the approach taken by PELF reveals contrasting perspectives in how people see themselves in relation to institutions and each other, and informs human rights discussions in which the capability to live a dignified life is the primary benchmark.

Methods and analysis

Data for this study are based on interviews and observations collected in February–April 2016, when PELF and The Carter Center, a health and human rights non-governmental organization (NGO) based in Atlanta, USA, undertook a survey of malaria and LF prevalence in extant *bateyes* nationwide (southwest, east, and north regions of the country).³⁰ Additional data come from a follow-up interview completed in March 2018.

During the 2016 survey, the lead author inter-

viewed 27 *batey* residents across three geographic regions to collect personal narratives of general life, hardships, and support systems in *bateyes*. These individuals were enrolled during surveying activities based on their personal and/or professional background and insight into daily life and local history of their *batey*. Interview participants were Haitian- or Dominican-born, ranged in age from early 20s to early 70s, and spoke in either Spanish or Kreyòl. Three were heads of their *juntas de vecinos* (neighborhood associations); two were community health volunteers in the *bateyes* where they were born. One woman was a school teacher in a *batey*. One man was the co-founder of a small advocacy group supporting the rights of Haitian migrants in the region. The rest were agricultural laborers, market vendors, or unemployed. Interview participants were selected through established networks with PELF colleagues, snowball referral from other informants, or relationships from previous fieldwork.³¹ An interview guide was initially developed around core themes such as migration, livelihoods, coping and support, health and disease, care-seeking, and the 2013 *Sentencia*. Perceptions and reported experiences with PELF were not explicitly solicited; rather, interviews with *batey* residents sought to capture their personal narratives and to provide space to articulate daily life and social exclusion from their points of view. The structure of interviews was adapted over time in response to findings.

The lead author also accompanied PELF colleagues during the 2016 survey to observe their day-to-day responsibilities, which included making initial contact with *juntas de vecinos*, supervising survey teams, and ensuring adequate follow-up treatment for survey participants who tested positive for malaria or LF. Over three months, the lead author accompanied PELF colleagues in both formal and informal settings, including community meetings in *bateyes*, regional public health offices, and “street-level” interactions with *batey* residents.

Based on established rapport developed during these accompanying activities, a follow-up interview was done in March 2018 with two in-

dividuals at PELF. Since 2002, both individuals have worked as *facilitadores* (facilitators) for MDA campaigns, tasked with fostering links between the elimination program and the *bateyes*. The purpose of this interview was to seek feedback on emerging themes from the 2016 interviews and gain additional insight into community engagement for LF elimination.

After providing oral informed consent, interview participants spoke with the lead author for approximately 1–1.5 hours, typically at their residence or work place. Interviews with *batey* residents were audio-recorded and then transcribed verbatim in the original language into Word documents. Field notes and observations were also typed as Word documents. All documents were then uploaded into MAXQDA software for qualitative analysis. To protect confidentiality of participants, all names appearing are pseudonyms. Ethical approvals for both the survey and in-depth interviews were provided by ethical review committees in the DR (CONABIOS), the University of Amsterdam, and Emory University.

An initial reading of all documents was done to develop and apply a coding scheme. *A priori* codes ranged from economy and labor; documentation; health care; feelings of unimportance; support/coping; and community engagement/mobilization. *In vivo* codes sought to link recurrent explanations, incidents, and other phenomena as emphasized by participants, often in their own wording or idioms. Examples of these codes include *afectado* (or “affected” by the *Sentencia*); *chache lavi/buscar la vida*, or “to look for life” in reference to migration or finding work; *pa gen vale/no vale nada*, or worthless; *moun politik/gobierno* to refer to public authorities, the government, and local politicians; and *tèt ansanm* (“heads together”) to refer to social support among the Kreyòl-speaking population.

Following code assignment, text segments were retrieved based on shared codes and re-categorized under two contrasting themes: 1) *batey* residents share feelings of unimportance, especially since the 2013 *Sentencia*; 2) despite their social exclusion, PELF has been successful in reducing LF through mutual

respect and interpersonal relationships.

Findings

“Dead but alive”: Social exclusion in DR *bateyes*

The *Sentencia* re-classified Victor Fernandez, a man in his late 60s who served on the local neighborhood association, as a foreigner in the land of his birth. His parents had come from Haiti in the 1940s and were issued identity cards by an *ingenio* (sugar company) in cahoots with the government. Although he possessed a state-issued birth certificate and *cédula* (state-issued identity card), Victor was no longer considered a Dominican citizen due to supposed problems with his parents’ documents—which had been issued by Dominican authorities in the first place.

Sitting in a plastic chair on his patio, Victor grew animated, and asked rhetorically:

The first Spanish who were born here, what blood did they have? They didn’t grow out of the earth like a plant. They came from somewhere else. We all did. We have the same rights, we are Dominican, but the laws say we aren’t.

He attributed the *Sentencia* to, “people *a nivel de arriba* [at the top] [...] a few powerful economic sectors” that sow division, which then trickles into daily life. For example, Victor had once been stopped on a bus and asked for his passport. In his telling, this was prompted by his darker skin, as lighter-skinned individuals were not asked to show theirs. “I only show my passport when I travel outside my country,” he responded firmly.

“Erasing history,” notes Paul Farmer, “is perhaps the most common explanatory sleight-of-hand relied upon by architects of structural violence.”³² Victor’s account forcefully pushes back against this erasure. He recalls that social exclusion on Hispaniola goes back a long way, from Spanish *conquistadores*, to the growth of Dominican sugar plantations that ensnared Haitian cane cutters like his parents, to the present day, in which his own life has been upended. This long reach of history figures into Victor’s interpretation of himself in

relation to others, including both people “at the top” and street-level agents, those tasked with the “dirty work” of selecting “good” citizens from the “bad.”³³ While he says that “we all” have come “from somewhere else” and “have the same rights,” Victor recognizes his own positionality in an unequal social order.

Other *batey* residents shared Victor’s diminished sense of personhood, that their lives were unimportant in the eyes of official institutions or authorities, whether sugar companies, the national government, or simply *gente de arriba*—“people at the top.” For example, another interview participant, a Haitian man in his 30s working as a market vendor, was told by an issuing office that his permit would last five years, only to discover that it was valid for only one. This bitter experience, along with not having enough time to comply with recent changes in documentation requirements, left him feeling that the Dominican government, “doesn’t consider us people.”

Being ignored or manipulated by public authorities has long been a part of life in *bateyes*. Antonio Guzman, a Dominican-born man who had risen to a supervisory role in the local sugar company in the north region before it closed over a decade ago, attributed a deep psychological wound to a lack of government concern:

What do you do when there’s no work? You humiliate yourself, you grovel, beg, and plead. This is what the government has done to us in the last 10 years. They’ve eliminated all sources of work by closing the ingenios. Agriculture has been completely abandoned. That’s why we’re in the state that we’re in.

Juan Carlos, an older man who had migrated from Haiti at age 12 and later became an advocate for migrants, shared an anecdote illustrating how *bateyes* could be manipulated for political ends. During the election campaign leading up to Joaquín Balaguer’s second administration (1986–1996)—one that breathed new life into Trujillo’s (1931–1960) *anti-haitianismo* (anti-Haitianism)—the government saw an opening to round up votes among the undocumented *batey* residents:

At the time, everyone was given a cédula to go vote for Balaguer. Later, we were told that the cédula was fake, that it was only given to us to vote in their favor. We didn’t know anything, but we voted, [because] that was their plan.

The 2013 *Sentencia* reinforced this pattern: taking away documents from Dominican-born persons of Haitian descent leaves them, as Juan Carlos said, *muerto con vida*—“dead but alive.” In his words, “These kids without documents, they can’t advance in life, they can’t go to school and find a good job.” His perspective was shared by two female community health volunteers, each in different regions of the country. One said, “If the child can’t study, they have to work hard, in the fields cutting wood to make charcoal,” while the other remarked, “If you don’t have documents, how can you care for your family?” Others linked unauthorized status to restricted mobility, expressly using the verb *to walk*. One woman said that documents were essential for those in *bateyes*, “so that they can walk,” while others would say that without documents, “you cannot walk far” due to risk of apprehension.

For those seeking to recover documents in the fallout of the *Sentencia*, interactions with local bureaucrats also generated sentiments of unimportance. One woman, a Dominican-born school teacher affected by the *Sentencia*, described the scene at the local registry office: “All they say are little words” (*palabritas*). “Without an important person (*alguien grande*)—they won’t make a case of me” (*no me van a hacer caso*), or in other words, they ignore me. Positioning herself in relation to “a big person,” one who can move the levers of clientelism, implied that she saw herself as powerless. Similar phrasing has been found among the Kreyòl-speaking population: Haitian migrants have referred to themselves as *ti malere*, or “little miserable ones,” toiling at the behest of *gwo nèg*, or “big men,” connoting smallness and disempowerment.³⁴

This sense of powerlessness derived not only from recent government decisions such as the *Sentencia* or bureaucratic obstacles, but also from government *inaction*—from lack of concern for material hardships in *bateyes* or lack of follow-through by those promising to improve life and livelihoods.

Like Antonio Guzman, who remarked on the humiliation felt by those left unemployed in the *batey* after closure of the local *ingenio*, Esther Beauvil, a Haitian-born woman living in the southwest region, also communicated the perceived slight from government inattention.

In 1998, she and her family lost their home in the southwest region to Hurricane Georges. Living in a small *batey*, they moved further inland to another *batey*. Years earlier, Esther had migrated from Haiti and married a Dominican-born man. In the time since they relocated, she worked as a cleaning lady in the homes of wealthier people in the capital, because in the *batey*, *bagay yo di*—“things are hard.” (Figure 1)

At the time of the interview, the country was in the throes of an election. It was not uncommon to see pickup trucks carrying giant speakers blasting announcements to vote for some candidate. Sitting in the shade of a small, scraggly tree, Esther looked around her in disgust. She said people here eat only what grows from their *conucos*, or subsistence gardens. There was no water source, no decent roads, and no schools. She said:

It's like the government doesn't even know there are people here. Only when there are elections will you see cars roll in with people to talk to us, and after, you'll never see them again. We'll vote for them, but they don't deserve it, because they don't remember us. The government doesn't sit down with us (Leta pa chitè avek nou).

In sum, for *batey* residents, the relations and circumstances that signaled their rejection ranged from the empty promises of politicians, lack of improved livelihoods, or gestures and “little words” at local bureaucratic offices. The social cues of exclusion extended onto the street. Some participants cited instances of being called names, based on some physical trait such as hair texture or skin tone, for presumably being Haitian. Drawing on the Kreyòl idiom *pa gen vale*, or worthless, an older man, who had come to the DR decades before, said simply, “When they say you have no worth, it means you are not a person.” At stake was both a sense of self-worth and a sense of belonging to the broader social body: of being a full-fledged *moun* (Kreyòl, person) or *reconocido* (Spanish, recognized) in Dominican society. In short, these accounts reflect the “desire

FIGURE 1. Scene from *batey*, Dominican Republic, 2016. Photo by Hunter Keys.



to be recognized as socially ratified persons.”³⁵

“Public, because it’s for everyone”: The approach of PELF

In March 2016, Yulisa Cáceres, a *facilitadora* (facilitator) and laboratory analyst for PELF, arrived late at night in a *batey* and knocked on the wooden door of a small, cinderblock structure. Earlier, this little home had been selected in the malaria and LF survey. Gertrude, a young Haitian woman who was living there with her husband and two children, had tested positive for LF antigen. Because antigen can persist after infection has cleared, night-time testing is required to test for the presence of LF parasites, which circulate in the blood stream primarily at night.

A light came on and a shirtless man unlocked the door and opened it a crack. He peered at the strangers on his doorstep, sheathed machete in hand. *Somos de salud pública*—“we are from public health,” said Yulisa. A few expressions in Kreyòl seemed to defuse any tension, and the man opened the door to welcome the PELF team inside.

Yulisa is in her 50s and has worked for PELF since 2002. She also assists a local non-profit that advocates for the rights of those left stateless after the *Sentencia*. In her words, the court decision “was an abuse.” She does not claim any Haitian descent, and explains, “I may not have the same culture [as those in the *bateyes*]. I cannot judge how people live.” Quite familiar with the poverty of *bateyes*, she went on. “I’m only there to give assistance or advice about health. If I see that you do not even have a table or chair, I won’t ask for a table and chair to do my job when I visit your home.”

Simple steps like these were, for Yulisa, *por la confianza*—to maintain trust. It would also seem as simple a matter as basic politeness. Still, others working for PELF remarked on the importance of maintaining trust with community members. One *promotora* (health promoter) described how some in her *batey* were cautious to approach another promoter in the area because she was known to gossip about her patients. To do the job right, she explained, “You have to know how to keep their trust.”

Yulisa completed several steps before going to Gertrude’s home. At PELF’s central headquarters, she reviewed the positive sample that had been collected weeks earlier. She then contacted the local health promoter in the area, and explained to the promoter that she would need to give advanced notice to Gertrude that another team would arrive for more testing.

Inside Gertrude’s home, a bare light bulb dangled overhead, casting a faint glow. *Ou met chitè, chitè*—“please, sit,” said her husband, offering their only piece of furniture aside from their bed: a little stool that barely rose more than a foot off the ground. True to her word, Yulisa declined the stool, preferring that Gertrude sit there for the blood draw. On the mattress were two infants sleeping quietly under a mosquito net, their soft breathing almost synchronized. The inside air was hot and stuffy. The high-pitched buzz of mosquitoes greeted the visitors, prompting Gertrude’s husband to take shelter under the mosquito net. With more frequency, Gertrude kept slapping at her legs, exclaiming with a little laugh, *Anpil moustik!*—“so many mosquitoes!” Yulisa drew the blood carefully, placed a drop onto a glass slide for later analysis, and packed up their materials. They told Gertrude they would return to provide treatment if her sample was positive (which it was, so they did). The team exchanged farewells.

Aside from following up with patients for treatment, facilitators like Yulisa are tasked with fostering relationships with *bateyes* to carry out MDA campaigns. Typically, their main point of contact in *bateyes* is at *juntas de vecinos* (neighborhood associations). The relevance of the *juntas* to daily life cannot be understated; as one association president explained:

The community must be empapada [literally, “soaked,” or here, infused] with the junta and the junta with the community. [...] What we look for is a way for the community to feel more united, that we all need each other.

Similarly, a traditional way in which rural Haitians band together to share tasks is called *tèt ansanm* (Kreyòl for “heads together”). In the DR, Haitian

migrants have expressed disappointment at the inability to form these support groups due to the transitory nature of migration or perceived misunderstanding with Dominican neighbors.³⁶ Still, in some *bateyes*, it appeared that residents tried to form groups like *tèt ansanm*, no matter how informal. For example, interview participants described *recolectas*, or collection drives, to help pay for medical care or food for those in need. “We live by the strength of our hands,” said a shop owner in one *batey*.

Collaboration with these support groups is central to the work of PELF. MDA efficacy is highly dependent on MDA coverage.³⁷ Thus, PELF extends drug coverage to as many eligible individuals as possible (excluding those who are pregnant or under two years of age), regardless of legal status, ability to pay, or seek care at a formal health structure.³⁸ One health promoter in the southwest emphasized the importance of reaching all persons in her work, particularly newly arrived Haitian migrants, who are often in dire need: “Some among them are sick, and they have nobody here to help them, no family, absolutely nothing.” Speaking Haitian Kreyòl is not usually a problem, either, she explained, because, “Some came from [Haiti], so we learned to speak Kreyòl. We’re joined together,” [*estamos ligados*] “Dominican and Haitian.”

Broadening the reach of MDA campaigns requires significant labor and resources, of course. Consequently, PELF engages with the community throughout the entire process: from initiating contact at *juntas de vecinos*, to conducting educative talks in the *bateyes*, to recruiting and training local volunteer *medicadores*, or medication administrators who go house to house.

The first step in this process involves identifying leaders at the neighborhood association or elsewhere and asking their permission to enter their communities. Working with these leaders, the PELF team then organizes larger meetings to explain the purpose of the MDA campaign and answer any questions. Yulisa and Wilson, another facilitator who has worked within PELF since 2002, underscore the need to explain everything in advance, including details of exactly how many tablets would be administered per person, so that,

as Yulisa says, “there will not be any surprises.” She goes further: “What is most important is community participation. [...] The person must feel like they are their own protagonist for their health.”

However, both Yulisa and Wilson emphasize that PELF does not broach the *tema caliente* (“hot topic”) of the *Sentencia*. While it is not within PELF’s mandate to address complex political issues directly, it was not lost on the PELF team that their work confronts problems tied up in a broader context of social injustice. As one figure within PELF confided, the situation of *bateyes* revolved around profit: “Exploitation would be far less if Haitians had rights,” because, as he went on, with legal status, they could then access social services and health insurance funded by employers and the government.

When entering *bateyes*, Yulisa explained that they take caution to explain that LF is a health problem “that affects everyone,” not just Haitians or Haitian migrants. Thus, everyone has a stake in resolving it. One community health volunteer echoed her perspective: “Because it’s called ‘public health,’ ‘public’ means it’s for everyone.”

“We are not nationalists,” Yulisa says. “We always say it’s a problem for the whole island, not just [Haiti]. [...] After all, mosquitoes don’t have passports!” Wilson adds, though, that because of migration, “so long as there are cases in Haiti, there will be cases” in the DR.

Discussion

While this study was not designed to capture perspectives of residents towards PELF, the findings point to widespread feelings of unimportance that contrast with the elimination program’s approach of non-discriminatory access to testing and treatment. The program’s success in achieving high MDA participation rates and reducing LF despite this context of social and legal exclusion suggests ways to narrow the gap between human rights obligations and the present reality of violations resulting from the *Sentencia*.

Fundamentally, these findings reflect opposing viewpoints over how people should be recognized

in Dominican society. From a judicial perspective, the 2013 *Sentencia* reclassified entire generations of Dominican-born, Haitian-descended people as non-citizens. In effect, the *Sentencia* relocated exclusionary practices to the bureaucratic office, where digital registry lists determine who may have access to documents, and consequently, to life chances.³⁹ This “modernizing” shift in tactics, of course, follows a historical trajectory. In the early 20th century, the illegal status of Haitian migrant cane cutters formed the basis for increased state control over their labor, leading to physical confinement on *bateyes* and periodic expulsions going well into the 1990s.⁴⁰ From a historical perspective, the *Sentencia* was but the latest strategy to enlarge the proletarian sub-class.⁴¹

For participants in this study, the *Sentencia* affected not only daily life but also their internalized sense of who they were as people, as *yon moun* (Kreyòl, a person) or *una persona reconocida* (Spanish, a recognized person). This assault on dignity was evident in the comment that it was as though, “the government doesn’t even know there are people here”; in the humiliation felt by those without jobs; in the description of those rendered stateless as “dead but alive”; and in the experience of a Dominican-born man singled out to show his passport on a bus. Social exclusion in the DR continues to shape how people see themselves in relation to the government and each other.

Counter-current to this dynamic, PELF, through its operational goal of mass drug administration, qualifies all residents in areas of LF transmission as deserving of attention, regardless of documentation or immigrant status. This approach helps to counteract a major consequence of being undocumented: exclusion from health insurance schemes offered by employers or the government.⁴² Indeed, as previous field studies have found, persons without identity documents are forced to pay out of pocket or receive less specialized care, even in the public system.⁴³ In their work, Yulisa and others explained that the disease was not isolated to Haiti, nor one brought by Haitians, but one, “for the whole island” to resolve. This global perspective makes everyone responsible for LF. For the PELF

team, the causative agent of LF went beyond the parasite, whose edematous effects on the body were depicted on informational posters carried door to door. Rather, LF was cause and consequence of poverty, migration, and disenfranchisement—distal forces, they admitted, that lay beyond the scope of their work.

Operationally, PELF recognized the need to collaborate with *bateyes*. Mobilizing communities entailed acknowledging local authority held by neighborhood associations, support systems that seemed to carry more respect among *batey* residents than the municipal or national government, whose candidates for office were said to make fleeting appearances motivated only by votes. Gaining trust was essential for approaching a population harboring deep skepticism of outsiders, particularly government agencies. Finally, trust and respect could be conveyed in simple interactions between PELF and those they try to reach—such as an unassuming attitude inside a home without a chair. Small gestures indeed, they nonetheless reflect an approach that recasts *batey* residents as participants in their own health, a rebuttal of the, “state politics of abandonment” that diminish their place in society.⁴⁴

By rejecting a discriminatory approach, PELF acknowledges the right of all *batey* residents to one specific aspect of the right to health—protection from, and treatment for, LF. This process presupposes that the lives of *batey* residents are worth reaching, regardless of whether political or legal circles have declared them illegitimate. Recognition of *batey* residents by PELF contrasts starkly with the *loss* of recognition accumulated over years of discrimination, structural violence, and the recent *Sentencia*. In a way, PELF has found itself in the space between the powerful and the weak, between a political and judicial system that considers *batey* residents as nothing more than cheap laborers, and the residents themselves, whose claims for recognition *as people* are at stake.

A picture of perceived social exclusion in *bateyes* is evident. Yet observations and interviews, as well as epidemiological evidence of reduced LF transmission, reveal features of PELF’s successful

community engagement that can help to overcome exclusionary experiences: knowledge of the cultural and historical context; legitimation of local political authority; representation of residents in key positions, such as health promoters and medication administrators; use of existing resources at primary care centers; opportunities for residents to voice concerns; and communication between PELF and target communities.⁴⁵ Respect has for its foundation, “the recognition [...] of certain powers and capabilities” among those to whom it is carried.⁴⁶ In a context where many feel deeply disrespected—if not altogether ignored—such an approach helps to bring human rights ideals somewhat closer to reality.

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