Chapter 4: Key Collaborating Partners: Civil Society, Communities, and the Private Sector

SUMMARY

To find and treat all people with TB and achieve the End TB Strategy milestones, countries must engage with civil society, community organizations and the private sector as partners at all stages of planning and implementing the response to TB. Civil society and community-based organizations must play a key role in the planning and provision of TB care by increasing awareness; active case finding; improving access to care; encouraging and supporting people with TB during the course of treatment; providing psychosocial support and reducing stigma; monitoring programmes; and facilitating community engagement in research and development. Private health care providers and businesses have an important role to play in providing, developing and partnering to deliver quality and affordable TB care, new tools, resources and expertise. Investments are required to strengthen health and community systems and public–private partnerships. A change in mindset along with an enabling environment is needed in order to meaningfully engage with communities and unlock the full potential of the private sector.

PRIORITY ACTIONS

National TB Programmes:

- Strengthen community health systems so that quality-assured TB care and support can be accessed locally.
- Engage communities from the start in designing and planning TB programmes and interventions, involving them as active partners in the implementation and monitoring of TB services.
- Partner with the private sector and labour unions toward scaling up access to TB care, establishing workplace TB policies and initiatives, and improving community outreach.

Donors and impact investors:

- Increase funding civil society and community organizations as part of efforts to end TB.

Private industry and businesses:

- Adopt non-discriminatory recruitment and retention policies, promote infection-free and safe workplaces, and provide their staff and families with good-quality and affordable TB diagnostic, treatment and notification services.
- Partner with national TB programs, TB organizations and community organizations in corporate social responsibility initiatives.

Civil society and communities as partners in the response to TB
The UN High Level Meeting on TB helped to shift the global approach to TB further away from “controlling” the epidemic to an approach that is required to end the epidemic. Far from the historical top-down approach through which TB was meant to be controlled, ending TB is radically different. Ending TB embraces an approach that empowers patients, survivors and communities and broader civil society as valuable partners.

Civil society and community-based organizations—including patient-based organizations, nongovernmental organizations, faith-based organizations, youth groups and community volunteers—are fundamental partners in the drive towards universal access to TB care. Community health workers and TB survivor peer-support networks both provide vital support to health systems in many resource-poor countries—and they can reach communities that are hardest to reach. Furthermore, they act as a voice for the most vulnerable, advocating for the needs of TB patients and advising on interventions that are feasible in their specific setting. Without their active involvement in the planning, implementation, and monitoring of TB programmes, the predictable result is often top-down disease programmes that might be aligned with global and national strategies but remain inefficient because they lack an understanding of the local context, community dynamics, and ownership.

To end TB, countries need to continue strengthening community health systems, where quality-assured health services are accessible locally, and where the community system is to both higher levels of the health system and to the national TB response. Civil society and community organizations must be engaged from the start in planning TB programmes, and involved as active partners in the implementation and monitoring of TB services. For example, social media and social audit mechanisms should be more widely used to enable patients, civil society organizations and community members to contribute to improving services and monitoring progress. For example, WHO’s Engage-TB guidance, developed in 2012, offers guidance to National TB Programmes on how they can effectively work with NGOs and civil society organizations that are not already working on TB.1

A key challenge in engaging communities and civil society is the relatively few individuals and networks committed to ending TB. This under-representation also has an impact on national and global planning, where the voices of civil society and communities are not always heard.

This is changing, however. Networks of TB survivors have grown organically in recent years, including TB People, TB Proof and We Are TB, adding to community coalitions such as the Global Coalition of TB Activists, the TB Community Advisory Board and the TB Europe Coalition. There is a need to further enroll and build the capacity of TB survivors to engage in advocacy and other elements of the TB response through participation in organized networks, forums and national, regional and global groups.

The TB community could further build its capacity by working even more closely with the HIV community. High rates of TB and HIV coinfection necessitate integrated approaches in key regions, especially Africa. This integration is crucial down to the community level. The TB

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community should also engage more with other advocacy constituencies that offer the potential for collaboration. This includes faith-based organizations, legal clinics, human rights organizations, anti-poverty and microcredit networks, and women and youth networks.

These endeavors will require significant increases in funding from advocacy donors, alongside increased action on the part of governments to include the communities affected by TB within decision-making bodies and processes.

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BOX 4.1: CIVIL SOCIETY NETWORKS AT GLOBAL AND REGIONAL LEVEL

TB affected communities, or communities of people affected by TB, refers to any person with tuberculosis or who previously had tuberculosis, as well as their caregivers and family members. In addition, TB affected communities refers to TB Key and vulnerable populations which can include children, health care workers, indigenous peoples, people living with HIV, people who use drugs, prisoners, miners, mobile and migrant populations as well as the urban and rural poor. Networks of people affected by TB, TB survivors and civil society now exist at the global, regional, national and subnational levels and further efforts are needed to strengthen these network and ensure their active role in planning, implementing and monitoring the TB responses, as well as demand creation for the best quality of TB services for all.

TB affected communities and TB survivors must play a leading role in global, regional, national and local level policy and programme prioritization, design, implementation, monitoring and evaluation. They can help identify and overcome social, political, cultural, legal, gender and economic barriers to accessing TB services, care and support. They are also in the unique position of being the experts of the lived experience of TB. They know the side effects, the stigma and discrimination, the isolation, the economic, physical and psychological burden, and, for many, the lifelong legacy of the disease. It is because of this they must be empowered to be both leaders and watchdogs in the TB response – making sure all other stakeholders are realizing their commitments and the rights of people affected by TB are being promoted and protected. TB affected community can therefore play a role that nobody else can play. It is a critical role, without which we will not end TB. And, this role must be acknowledged as an expertise and be funded accordingly.

This principle that TB affected communities are not just recipients of services but active agents in the TB response; that TB patients are people first and patients second, and that while governments, policies, guidelines and donor priorities may shift, the community remains, has seen the increased emergence of TB survivors and TB affected communities claiming their place as equal partners in all aspects of the TB response.

The mobilization of TB affected communities has materialized in different ways. Globally there are two networks:

- Global Coalition of TB Activists (GCTA).

This network has been leading advocacy efforts focusing on the stigma faced by people affected by TB.
• TBpeople
This network is new but has grown rapidly, now with national level affiliates. TBpeople led the development of the Declaration of the rights of people affected by TB in 2018-19.

At the regional level, there are networks of TB affected communities and civil societies:
• ACT in Anglophone Africa
• DRAF TB in Francophone Africa
• ACT! AP in Asia Pacific
• Americas TB Coalition in Latin America and the Caribbean
• TBEC in Europe and Central Asia

At the national level there are also efforts being led by organizations and networks for example
• TB Proof in South Africa
• Club des Amis Damien in DRC
• We Are TB in the United States

In addition there is the Global Tuberculosis Advisory Board (TB CAB). This is a group of research-literate community activists advising product developers and institutions conducting clinical trials of new TB drugs, regimens, diagnostics and vaccines; and, providing input on study design, early access, regulatory approval, post marketing and implementation strategies.

The need for a global umbrella structure for community groups
With community-based networks, groups and coalitions existing in many regions, there is need now for an umbrella structure to promote knowledge-sharing, coordination and joint activities at the global level, with a focus on ensuring government accountability for fulfilling their UNHLM commitments. Such an umbrella structure should be representative and allow experiences from the grassroots level to be elevated to inform global policymaking and advocacy.

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Toward meaningful engagement with communities
The UN political declaration on TB affirmed that people with TB need integrated care and support, including from the community, including psychosocial, nutritional and socioeconomic support for successful treatment, and the reduction of stigma and discrimination. In response, UN member states committed to “developing community-based health services through approaches that protect and promote equity, ethics, gender equality and human rights in addressing tuberculosis by focusing on prevention, diagnosis, treatment and care, including socioeconomic and psychosocial support, based on individual needs, that reduce stigma, and integrated care for related health conditions, such as HIV and AIDS, undernutrition, mental health, non-communicable diseases including diabetes and chronic lung disease, and tobacco use, harmful use of alcohol and other substance abuse, including drug injection, with access to existing and new tools.”

As core partners in international and national TB activities, TB-affected communities should be brought on board at the start of the planning process before new TB interventions or initiatives
are designed. TB programmes should include civil society organizations (CSOs) in core activities, inviting them to attend key meetings, such as those for strategy setting and programme reviews, and to sit on scientific boards. The ultimate aim should be well-designed TB services owned and sustained by communities, working in collaboration with the government and other stakeholders.

The Global Plan recommends a variety of ways in which communities should be more deeply engaged in the various aspects of the TB response. Communities should be involved in the response to end TB through both community-based efforts and community-led efforts. Community-based efforts are those that are carried out locally in settings outside of the formal health care settings. Community-led efforts are those that are managed, governed or carried out by members of the community. Both community-based and community-led efforts should link to the formal health system.2

In all cases, national TB programmes should periodically assess progress and impact that engagement with civil society organizations and affected communities has on the fight against TB, and to direct resources where they are shown to be most effective.

Community system strengthening

Community system strengthening (CSS) is a useful approach to planning engagement with civil society and affected communities—particularly to help TB programs fulfill their commitments to human rights and gender equity.3 CSS refers to supporting the development of informed, capable, coordinated and sustainable structures, mechanisms, processes and actors through which community members, organizations and groups interact, coordinate and deliver their responses to the challenges and needs within their communities.4 By considering communities and their role as part of the larger health system, CSS allows for an analysis of the different facets of that system, how they are interconnected, and what aspects need to be strengthened. With the skills and resources, communities can help health systems determine the needs of people with TB, advocate for better services and hold donors and governments accountable.

Community organizations hold critical knowledge about the health needs of and feasible interventions for their communities. While TB survivors, civil society and community representatives often have abundant grassroots expertise, they might need capacity-building and support, for example, to meaningfully participate at high-level meetings, to engage with international organizations and governments, conduct outreach to the news media or engage in processes through which policies are shaped.

To hold national governments accountable for fulfilling their need to “develop integrated, people-centred, community-based and gender-responsive health services based on human rights,” will require human-rights-based advocacy, including advocacy for gender-sensitive health programming. Advocacy capacity-building should therefore include training in the use of

3 Ibid.
4 Ibid.
human rights impact assessment tools. Such tools can enable communities to anticipate and respond to the potential human rights impacts of government, trade, and national and corporate policies related to TB.

The Global Fund has produced a technical brief on community systems strengthening that goes into further detail about benefits and approaches to CSS with respect to TB.\(^5\)

**Community-based efforts**

**Community-based monitoring**

To shift the paradigm toward ending TB, national TB responses should prioritize and invest in efforts that respond directly to the needs of communities affected by TB. To this end, community-based monitoring (CBM) can help to bridge the gap between the health system and the community.

CBM in TB is an intervention, driven by local information and community needs, that aims to increase accountability in the TB response so that essential, quality and timely TB care and support services are available, accessible and acceptable to all, especially those who are vulnerable, underserved or at risk of TB. By engaging people with TB and affected communities to provide feedback and report barriers that inhibit access to services, CBM can improve the responsiveness and equity of TB care and support services, inform the design of TB programmatic interventions and policy decisions and evaluate the TB response. CBM can help to reach the unreached by generating information used to close the gap in the number of people who lack access to TB care. It also facilitates public participation and strengthens local decision making on issues that are important to both the community and the TB response, including complex social, economic and human-rights issues, which result in millions of people with TB being missed by the health system each year.

Since 2017 the Stop TB Partnership, with support from USAID and the Global Fund to Fight AIDS, Tuberculosis and Malaria, developed a community-monitoring framework and digital solution platform called OneImpact to facilitate community-based monitoring of the TB response. OneImpact is currently supporting eight countries to implement the intervention.\(^6\)

**Engaging community health workers to raise awareness and reach the unreached**

Community health workers play an important role in reaching people who are missed by health systems, helping to fulfill governments’ commitments to “leave no person behind.” Through community outreach and educational programmes, community health workers encourage people who have TB symptoms to contact a health care worker or visit a health facility. When people are not able to travel, community workers can also help to transport sputum samples to the nearest health facility for diagnosis. Community health workers can also aid in the conduct of TB contact investigations, identifying household members who need to be screened and who are

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\(^5\) Ibid.

eligible for TB prevention, diagnosis and care. In fact, TB diagnosis is often delayed as people
sick with TB shop around for diagnosis and treatment, leading to unnecessary out-of-pocket
expenses. This out-of-pocket spending before receiving a reliable diagnosis is a major factor that
causes the catastrophic costs associated with TB. Encouraging people with TB symptoms to seek
appropriate medical care relies on the trust and peer-to-peer relationship that a community
representative can bring (Box 4.2).7

The participation of existing community health workers in such active case-finding initiatives
has improved case detection and treatment outcomes.8 However, their role has yet to be
maximized. One way to work with community health workers to actively identify persons in
need of TB screening and care is to integrate TB community outreach with HIV, maternal and
child health or other outreach programs.

Engaging traditional healers

Community-based systems can play a transformative role by linking informal providers with the
formal health system. A major challenge in TB care is that many people in low-resource, high-
burden countries who have symptoms first seek care from traditional healers or pharmacists,
rather than from public health clinics or hospitals. TB programmes need to more actively reach
out to these traditional healers and pharmacists and work them to provide referrals to health
centers.

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Box 4.2 Ethiopia’s health extension workers

In Ethiopia’s rural Sidama Zone, health extension workers (HEW) were trained to work in their
communities to identify people with TB symptoms, collect sputum samples, and prepare slides in
the field for testing before being transported to the laboratory for staining and reading. More than
1,000 HEWs collected sputum samples from more than 200,000 people with TB symptoms and
identified more than 17,500 people with smear-positive TB. This intervention doubled the
number of people put on treatment in a zone of more than 3 million people. In addition, the
HEWs provided treatment support, with treatment success rates improving from 77% to 95%.

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Providing psychosocial support and links to social protection

Completing TB treatment can be challenging. The treatment is lengthy and inevitably has side
effects, making counselling and support a critical part of comprehensive TB care. Community
members, who may have had TB themselves, can help to ensure that TB patients receive the
psychosocial support they need to successfully complete TB treatment.

notification and improve treatment outcome in southern Ethiopia. PLoS ONE. 2013;8:5
(http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0063174).
8 Ibid.
Travelling to clinics to access treatment can be expensive, especially for people living in remote areas. It can also mean that people with TB lose income in the process of seeking treatment. Community members can help to ensure that people with TB are linked with social protection schemes, such as food vouchers or conditional cash vouchers for treatment support.

Faith-based groups of all religions are also a vital resource for community-based care. These groups, along with other community-based workers, can help to provide palliative care to people with TB at home—a service that is beyond the capacity of most health systems.

**Community-led efforts**

**Eradicating stigma**

There is still considerable stigma surrounding TB. Eradicating this stigma is a crucial component of encouraging people to seek care and to supporting them throughout the course of TB treatment. For many people affected by TB, the greatest challenge they face is stigma. Stigma can involve stigma from family or the surrounding community, stigma from coworkers or healthcare workers. It can even include self-stigma, where people with TB internalize feelings of shame or guilt for having TB.

Through the UN HLM political declaration on TB, national governments committed to “promote and support an end to stigma and all forms of discrimination, including by removing discriminatory laws, policies and programmes against people with tuberculosis, and through the protection and promotion of human rights and dignity, as well as policies and practices which improve outreach, education and care.” Since stigma is rooted in social and cultural perceptions, including gender, in addition to laws and policies, education campaigns in communities will be important for helping to break down misconceptions and biases that lead to stigma and discrimination. Social media and other digital platforms can play an important role in eliminating stigma as well as identifying and overcoming other social barriers to accessing TB services and care. The more that communities are meaningfully engaged, and the more that TB survivors are empowered to advocate, to engage in TB decision-making processes and to assume leadership roles in TB efforts, the more stigma will diminish. Where discriminatory laws remain, advocacy for law reform will be crucial. In all cases, social media can play an important role in eliminating stigma and overcoming other social barriers.

**Engaging communities in research**

Engaging TB-affected communities in all aspects of research—from early-stage research to the design of clinical trials and the delivery and large-scale uptake of successful innovations—will help to make communities equal partners in the fight against TB. All researchers and sponsors should develop community engagement plans and take steps to include affected communities, patient groups and civil society in TB R&D. In fact, community members themselves are organized and ready to advise research institutions on how to optimize their engagement with communities for research purposes.¹ Chapter 6 of the Global Plan addresses community engagement in research in more detail.

Providing funding support for community capacity-building

Consistent, sustained investment in community system strengthening is vital to realizing the full potential of communities in the fight against TB. Donors and impact investors should consider funding civil society and community organizations as part of their effort to end TB. Resource needs are discussed in detail in Chapter 7.

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BOX 4.3 Parliamentarians Leading the Fight Against TB

Since the UN High-Level Meeting on TB resulted in a Political Declaration endorsed by Heads of State, Members of Parliament (MPs) around the world have mobilized to take the outcomes of the Declaration back to national parliaments for implementation.

Parliamentarians are holding governments to account through the creation of national TB caucuses which are independent networks of MPs within the countries. These caucuses are a powerful channel to raise awareness on TB, and consequently on the UNHLM Declaration targets.

With the support of the Global TB Caucus, national caucuses were launched in Brazil, Denmark, Eswatini, Paraguay and Romania in 2019, which takes the total to 49 worldwide. MPs from 93 countries reported taking parliamentary action on the UNHLM targets in 2019.

The Global TB Caucus (GTBC) is an international network of over 2500 Members of Parliament (MPs) in over 150 countries that works to build the political will to end TB. It focuses on supporting decision makers who are engaged on TB and prepared to take impactful actions such as engaging Ministers of Health or deploying parliamentary processes to advocate for greater investments in TB.

MPs secured budget increases in several countries, including the Netherlands, where the Hon Anne Kuik worked closely with KNCV to add an additional US$ 5.5 million during budget negotiations towards global implementation of new TB diagnostics. In Kenya the Hon Stephen Mule successfully raised nearly US$ 2 million for the national TB budget.

At the global level, the Caucus brings MPs together to share their experiences at Summits, including the African TB Summit in August 2019 which brought together over 40 MPs from the region. This cooperation encourages MPs to work at a regional level within political platforms such as APEC, AU, G7 and G20, to bring TB forward on the international agenda.

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Community system strengthening

To build effective community systems and to meaningfully engage TB survivors and TB key affected populations – a number of elements are required:
Mobilization: TB survivors must be mobilized, engaged and supported for coordination. Efforts are required to bring those who have survived this experience together and ensure that this mobilization can be sustainable. Leveraging the support of established civil society organisations is critical in the process of building or strengthening networks.

Capacity Building: Building the capacity of TB survivors to effectively contribute is essential. This includes developing advocacy skills, enhancing TB and TB treatment literacy, investing in development of capacity to counsel and support peers, to monitor, report and advocacy on issues including drug stockouts, drug side effects, human rights violations, stigma and discrimination, funding shortages or inefficiencies, barriers is access to new tools, and broader accountability.

Enabling Environment: TB survivors must have a seat at the decision-making table. While telling the story of the lived experience of TB can be compelling, it is the role of catalysts of programmes and policies that must be further advanced. For this to be effective, representatives of TB affected communities must develop a constituency who they consult and report back to. They must also be given the time and resources to prepare and strategise on key decision points – ensuring the voice of TB communities resonates through every TB discussion at every level.

Meaningful Engagement: Community systems for meaningful engagement, must receive the investment they need to become sustainable. They are not a luxury or a side note. As is highlighted in the UNHLM TB Political Declaration, TB affected communities and civil society are a critical element of the TB response that is beginning to emerge and can be a game changer for national programmes and millions of people impacted by TB every year.

Partnering with the private sector

In the context of the fight against TB, partnering with the private health sector encompasses the following stakeholders:

Partnering with private-sector health-product manufacturers

Commercial manufacturers, including manufacturers of laboratory equipment and vaccines, contribute directly to the research and development of new tools, and the production and supply of diagnostics and drugs to meet the needs of TB programmes and people with and affected by TB worldwide. Public-private partnerships with such companies are essential for fast-tracking the development of new tools, as well as for making drugs, diagnostics and vaccines affordable and accessible to people with TB. [TK UPDATE WITH NEW EXAMPLE AFTER 31/10.]

As new diagnostics, drugs and vaccines are developed for TB, such partnerships are needed to play a key role in providing access for people with TB. Partnering with private sector manufacturers of TB diagnostics and drugs is also important to ensure a steady supply to match demand, especially during the rapid scale-up of services.

Partnering with industry outside the health sector
Private industry is needed in the fight to end TB in two ways: by ensuring their workplaces follow best practices for preventing TB transmission and for providing for TB care and support for staff and their families, and by undertaking corporate social responsibility (CSR) activities. Industries and businesses, especially those that are labour-intensive, need to adopt non-discriminatory recruitment and retention policies, promote infection-free and safe workplaces, and provide their staff and families with good-quality and affordable TB diagnostic, treatment and notification services. National TB programmes and TB organizations can partner with businesses to provide staff training and to assist in the development of workplace TB programs, establishing links between those programs and the health system.

Efforts to end TB should engage corporate CSR initiatives. This is an important area for further engagement between TB programmes, their stakeholders, and businesses. Financial and in-kind contributions from the private sector are critical to progress in many areas, particularly in innovation, the use of information technology, and logistics management. Businesses with products and services that reach large populations may provide opportunities for public education and community outreach. Co-branding partnerships with the health sector could help raise TB awareness and eradicate stigma. Businesses could work with national TB programmes to help create TB-free districts or cities, or to fund feasibility studies for impact bonds or other innovative interventions.

Partnering with the private health care system

People in many countries prefer private sector health care because of its ease of access and the perception of higher quality. In a number of countries in Asia, a substantial proportion of people with symptoms of TB, including the poor, seek care first at private clinics. However, in most country settings, only a small proportion of private providers refer or notify to national TB programs those patients who they diagnose with and treat for TB. There is therefore much greater potential for making the private health system a true partner in TB care and prevention and addressing case notification gaps.

NTPs face major constraints in their efforts to engage with the private sector to scale up TB care, chiefly a lack of funding or capacity. Successful projects have addressed these challenges by investing in private intermediary agencies and creating social business models for the provision of quality TB care. Such models have not derailed the business models of private health care providers, but have worked with them synergistically to improve quality, affordability, and public health responsibilities. The use of digital health tools and innovative voucher-based reimbursement systems has also contributed greatly to the success of these projects.

Countries should work to secure adequate resources to implement and scale up an appropriate mix of the following private health-sector engagement strategies:

a. Sharing the burden of engaging numerous independent private practitioners with private “intermediary organizations” that can establish and scale up social franchising and social business models; NGOs with the capacity and skills to work with private practitioners; and professional societies and associations
b. Optimizing and expanding engagement with large hospitals, academic institutions and NGOs

c. Mobilizing and supporting corporate and business-sector health services in order to initiate and expand workplace TB programmes to serve workers, their families and communities

d. Engaging communities and civil society to seek care from and promote private providers offering high-quality TB care

e. Enforcing mandatory TB case notification through simplified and user-friendly digital tools, the rational use of TB medicines, and certification and accreditation systems to identify and incentivize collaborating providers

It is also important for national authorities and international donors to recognize that, in a number of settings, people have more confidence in the private health sector. Investments should therefore be made to strengthen both public and private sectors in order to help scale up good-quality, affordable TB care in both sectors.

Investment in public–private partnership approaches to strengthening private sector TB care is important for all countries. The Global Plan highlights this need particularly in two of the nine settings: Setting 6 (middle-income country settings with a moderate TB burden) and Setting 7 (India). Even in countries where most TB treatment is handled by the public sector, engagement with the private sector is still required for referrals and early TB diagnosis and treatment. The resultant reduction in diagnostic delay could have a major impact on reducing TB transmission.

**Partnering with labour unions**

National TB programmes should work with labour unions to create and enforce workplace provisions that reduce the risk of exposure to TB and provide access to care and support for those affected by TB, including for TB prevention. This is especially important for industries where workers are at high risk of TB, such as the health care and mining sectors. Unions can help to put in place strong workplace programs and national laws and policies that eliminate discrimination of people with TB, ensure safe environments with regard to TB, and enforce best practices and human-rights based policies with regard to migration and treatment of foreign workers.