

Maximizing impact through advocacy

Unit 14

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**Cover photo:** Boston-area students on the annual Urban Walk for Haiti



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# Maximizing impact through advocacy

We call upon HIV/AIDS activists and activists working on other health issues, including primary health care and the social determinants of health, to join forces in an international movement for the Right to Health.

- Declaration of Solidarity for a Unified Movement for the Right to Health<sup>1</sup>

### INTRODUCTION

A dvocates often work in the context of legal rights, advocacy efforts are not limited only to this constituency. Rather, advocacy work involves gaining the support of others to influence local situations, national and international policies or programs, and to move forward an agenda for change. Your organization might engage in advocacy by speaking out, drawing attention to an important issue for an individual patient, a vulnerable group or a community, and directing decision makers toward a solution. The issues you advocate for may change in response to specific events, but they will and should remain rooted in the principles and vision that guide your work. PIH's advocacy efforts focus on raising the standard of health care of the world's poor through action. While much advocacy (including that of PIH) uses ethical or moral arguments that might help persuade others to improve the lives of the destitute sick, PIH concentrates especially on service delivery in order to show, as clearly as possible, how positive results from the programs at the sites and their impact on local communities make the case for change.

In the early stages of your work as a program manager, you may not think about engaging in advocacy activities. Meeting the challenges of getting the site and programs up and running can be so demanding that your role in advocacy activities may be limited. However,

<sup>&</sup>lt;sup>1</sup> Partners In Health. (2009). *Declaration of solidarity for a unified movement for the right to health*. Boston, MA: Partners In Health. Retrieved online at: *http://act.pih/page/s/declaration*.

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in your daily interactions with patients and community, you will have many informal opportunities to explore how you might meet needs that extend beyond the basic objectives of your programs. Your role in advocacy might include listening to patients' needs; raising the standard of care and introducing new treatments for patients; and pushing beyond medical interventions to tackle those barriers of poverty that prevent patients from living healthy, dignified lives. Your advocacy efforts will help maximize the impact of your programs on the community you wish to serve.

One challenge of such advocacy is that it usually means working to change attitudes, policies, and sometimes even institutions themselves. As your programs grow and your commitment to the community is reflected in the health care and other services you deliver, the community can begin to trust your work on their behalf. This trust can help further community support for your program with officials in the Ministry of Health (MOH), other local and national officials, and often also with national and international bodies who set standards and provide resources. Bear in mind, however, that you may encounter resistance in these advocacy activities. Although PIH works in partnership with local institutions and within the bounds of local mores, advocating for the rights of the poor can also challenge existing interests and power relationships. To help overcome those factors that block your patients' access to health care, you will need to practice a delicate balance of patience and respect in all relationships. Providing clear evidence of your program's effectiveness to demonstrate the impact of your work on the community, increasing the strength of your voice by collaborating with others, and using a variety of media to disseminate your key advocacy issues are all important tools that will help you garner support to make the changes your community needs.

### **1.** GOALS AND OBJECTIVES

When shaping your advocacy framework, think first of all about the underlying mission and goals of your organization. The key principles that drive this vision should also inform your advocacy efforts.



Figure 1: A group of men in Lesotho paint "Men vs. AIDS" on the huge rock overlooking their village

## PIH NOTE

The conviction that health care is a human right is based on both our service to poor communities and broad international human rights consensus. Article 25 of the Universal Declaration of Human Rights states that "everyone has a right to a standard of living adequate for the health and well-being of oneself and one's family, including food, clothing, housing and medical care."<sup>1</sup> At PIH, this rightsbased perspective is the framework for our advocacy. In addition, we believe that it is only through governments that these basic rights can be sustained long term; the belief drives our commitment to working with and through the public sector.

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<sup>1</sup> United Nations Office of the High Commission for Human Rights. (1948). Universal declaration of human rights. Retrieved online at: *http://www.ohchr.org/EN/UDHR/Pages/Language.aspx?LangID=eng.* 

#### **1.1** Identifying issues

Your decisions about which issues you choose for advocacy will also be guided by the needs of the people and communities you serve. Good advocacy depends heavily on understanding the local context. (See *Unit 1: Learning about the local context* for more information.) Both listening to your patients and listening to local community groups help you begin to identify the social and economic issues that affect your patients' health. Practicing advocacy based on sensitive perceptions about your local community can help you determine when and how to push traditional boundaries of health interventions in resource-poor countries. A steady focus on learning about the local context is essential to your efforts to work for policies and approaches that will constructively address conditions of poverty. Some questions to ask yourself, your patients, and staff include:

- Are your programs and services effectively responding to patients' health needs? If not, what specific obstacles are standing in the way of good healthcare delivery?
- Are there new approaches, changes in treatment, or policies that you could put in place and begin to practice?
- Are there people in the community who have not received health care? How can you reach them?
- What other factors have a negative impact on their health status? What policies can you change or adapt to overcome these problems?

# PIH NOTE

In recent years, PIH has focused its advocacy efforts on changing policies on four critical issues. First, we challenged the policy that expected community health workers to be unpaid volunteers, because we demonstrated that health system strengthening in resource-poor settings could happen if trained, paid community health workers were able to alleviate the severe shortage of healthcare workers. Second, we advocated to change the international lack of support for the Haitian government that impeded democracy and social sector development, especially after recent natural disasters. Third, we questioned the policies that force the poor to rely on imported food instead of expanding local food production, because food that is only available as expensive imports undermines food security, especially marked in poor communities. Fourth, we voiced public concern about the international community and individual governments' funding cuts for health.

### **1.2** Determining advocacy objectives

Once you have identified your priority advocacy issues, narrow your focus into attainable objectives to increase your chances of success. Your objectives will depend on your active engagement of three spheres of influence that may be necessary to reach your goals: patients, community, and policy makers. Sometimes your advocacy may require you to engage in all three spheres at once to encourage effective discussions, collaboration, and results.

When defining your advocacy objectives as they relate to these three spheres, think about:

- What outcome is desired?
- What obstacles hinder that outcome?
- How might the obstacles be eliminated?
- How can the community become engaged?
- How will you target those decision makers who can affect the outcome?
- What resources do you have to work with?
- Who and what organizations are available to work with you in collaborative support?
- How soon do you want to see results and what time frame is realistic?

**TIP:** Highlight the policies and approaches you want to change when developing your advocacy objectives.

### 2. ADVOCATING FOR PATIENTS

Advocacy that helps your patients can take many forms. The most basic form of patient advocacy is the work you do in caring about each individual patient, and your commitment

to do everything possible to improve his or her health. However, often patient advocacy also means advocating for changes in the healthcare system itself. System changes are often needed to make sure that all patients—and particularly the destitute sick—receive highquality health care, by changing policies and institutions that do not provide such care.

### **2.1** Working with patients

Patients, particularly those in resourcepoor settings, may have low expectations for healthcare services in terms of both quality and access, based on their experiences. Leveraging resources on their behalf can raise patient expectations about the quality of health care to which they are entitled and can build their confidence in your organization's commitment. As they see what benefits your programs can bring, patients will recognize that tools to prevent, treat, and cure medical conditions are essential to their right to health. Your organization can demonstrate its commitment to patients by:



**Figure 2:** Staff, community members, and patients working in a demonstration garden at the health clinic in Nohana, Lesotho

- Addressing the challenges that poverty and marginalization pose to patients in their daily lives
- Establishing a facility that provides high-quality care and treatment
- Making the facility accessible to all patients
- Engaging skilled staff who treat patients with respect

# PIH NOTE

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PIH collaborated with mental health clinicians in Haiti to develop the Tout timoun se moun ("Every child is a person") program for HIV-affected children and their families. This program focused on reducing psychological symptoms and improving psychosocial functioning among youth ages 10–17 years and their caregivers, many of whom were HIV-positive. At the outset, we encountered high levels of symptoms and impairment in the participants' daily activities along with a sense of hopelessness. However, over the course of the one-year program, the participants felt greater support from each other. Based in part on finding strength from the group and the skills of the facilitators, children and their caregivers improved in psychological health, but also felt stronger in confronting HIV-related stigma. The patients and their children became advocates for themselves and for others affected by HIV/AIDS. One HIV-positive caregiver stated: "I felt embarrassed because people said bad things about me, I was very discouraged. Now I feel as though I have more strength, and I don't think about what others have to say about me." Another participant expressed similar sentiments: "Before I had a lot of problems because my friends and neighbors talked badly about me. Now I feel comfortable, I don't let things like this give me problems anymore." These experiences were shared with the global community at the XVIII International AIDS Society conference, advocating for confronting HIV-related stigma more broadly.<sup>1</sup>

<sup>1</sup> Mukherjee, J.S., Eustache, E., Oswald, C., Surkan, P.J., Ermaze, L., Scanlan, F., Wong, R., Li, M., Leung, L., Smith Fawzi, M.K. (2010). Standing up for our rights—an intervention that promoted HIV-positive caregivers and their children to plan for their future and play a more active role in their community. Poster presented at the XVIII International AIDS Society conference, Vienna, Austria.

Patients are often your best advocates. Their personal stories can make the strongest case in the community for how treatment or changes in care can improve health. You can also engage current and former patients as part of your staff, employing them in different roles. Patients might, for example, serve as community health workers or as HIV/AIDS counselors. In Lesotho, PIH patients advocate with other patients for the benefits of being tested for HIV/ AIDS. Photographs of one patient before and after being treated for HIV/AIDS is visible to all who visit the hospital in



Figure 3: New-born triplets with their mother, grandmother, and social worker in Rwanda

Maseru, Lesotho's capital. These photographs inspire both staff and patients to get tested and seek treatment.

**TIP:** Patients can become champions for your work, and strengthen your links with the rest of the community.

# PIH NOTE

Each year in Haiti, Zanmi Lasante (Creole for "Partners In Health") holds a symposium on health and human rights, at which patients and their families, community members, staff, teachers, students, government officials, and other healthcare providers gather to advocate for those living with HIV/ AIDS in Haiti. In 2001, on World AIDS day, the gathering included a group of about 60 patients living with HIV/AIDS who came prepared with a declaration they had drafted regarding the right of poor people with HIV/AIDS to receive modern, effective therapy. At the symposium itself, about 100 people who were living with HIV/AIDS and on antiretroviral treatment (ART) presented their main challenges to an audience of about 2,000. They called on the pharmaceutical industry, decision makers in wealthy countries, and all those in positions of influence to act together in new ways to slow the AIDS epidemic. The result of this patient-based advocacy was a document, "The declaration of Cange,1" which calls for solidarity and for the right to health care. While such a document is only a first step toward making changes in healthcare delivery, mobilizing the voices of patients and the community to address those who make policies helps to ensure that improvements in care and treatment for those living with HIV/AIDS will respond to real needs.

<sup>1</sup> Zanmi Lasante/Partners In Health. (2001). The declaration of Cange: World AIDS Day 2001. Retrieved online at: *http://www.pih.org/publications/entry/the-declaration-of-cange-world-aids-day-2001.* 

### 2.2 Working with staff

Advocacy includes encouraging your staff to advocate on behalf of patients. When you listen to staff and respect their skills, you support and affirm their abilities to treat and work with patients. Formal training opportunities that you offer to increase these skills also function to advocate for both patients and staff, making it possible for staff to apply the latest advances and best practices to their patients. (See *Unit 6: Improving programs through training*.) Informal day-to-day mentoring between staff members also advances learning and strengthens your staff's ability to act on the core values and the principles of your organization in the programs and services they offer. When you make sure that staff have the tools they need—medicines, supplies, and adequate facilities—you also advocate on their behalf to help them improve patients' well-being, often in very difficult circumstances.

# PIH NOTE

After graduating from the Medical School of the National University of Rwanda, new doctors must work two years in a rural district hospital to repay the costs of their education. This training obligation can be an opportunity to equip new physicians to be effective patient advocates. When all nine of the top nine ranked doctors from one year's graduating medical school class chose to work at PIHsupported district hospitals, we asked them why. One physician answered that the rich learning environment of these hospitals allowed him to flourish and to acquire expert knowledge and skills. Other new doctors said they wanted to serve the poor and the sick, and that at PIH-supported sites, even the poorest patients had access to high-quality care. Your hiring policy can also advocate for staff and patients by engaging as many local people as possible to work at the site. (See *Unit 5: Strengthening human resources.*) In addition to providing muchneeded jobs, hiring local people makes sure that your staff will, as members of the same community as patients, know firsthand what their patients face in daily life. Such knowledge can help patients and staff work together on the more deeply rooted societal challenges responsible for poor health in the community.

Community health workers (CHWs) can be powerful advocates for the psychosocial welfare of their patients. As neighbors of the patients, living in the same



**Figure 4:** After the 2010 earthquake in Haiti, Zanmi Lasante set up a mobile clinic that received over 500 patients per day

communities, CHWs understand the strains, stigma, and social isolation that often accompany illness. CHWs work with patients to overcome these pressures and engage the rest of the community in changing these attitudes. In a survey of patients carried out during the pilot phase of PIH's work in Rwanda, for example, one patient commented that the CHW "Helps me with my problems"; another experienced, "No stigma. [I was] free to share with him"; while a third patient received "emotional support."<sup>2</sup>

### PIH NOTE

Since 1998, the community-based approach has been adapted in Boston, where ill, marginalized HIV/ AIDS patients are cared for by community health workers in the Prevention and Access to Care and Treatment (PACT) project, a joint effort of PIH and Brigham and Women's Hospital. The CHWs work with patients who have difficulties adhering to HIV/AIDS treatment: they make weekly home visits and provide harm-reduction training, education materials, and prevention case management. CHWs also accompany patients to important medical and social service appointments, preparing them for the visits, reviewing information with them, and ensuring that the treatment recommendations are understood and acted on within the context of the patients' lives. Because these community health workers come from the same communities as their patients, they are uniquely qualified to deliver individualized care: they accompany the patients and advocate for them, "empowering, not enabling them."<sup>1</sup>

<sup>1</sup> Behforouz, H. (2009, December 21). Health reform lessons, via Haiti and Peru. *Boston Globe*.

<sup>&</sup>lt;sup>2</sup> Government of Rwanda. (2007, November). *Rwanda rural health care model: A comprehensive approach to rural health.* Kigali: Government of Rwanda.

In addition to engaging CHWs to advocate for your patients, you may also ask for help from staff with relevant experience in patient advocacy at the local level. Inviting input from those who have faced similar challenges can inspire your organization's staff to deliver high-quality health care for their patients.



**Figure 5:** A health promoter from PACT in Boston helps a patient adhere to her drug regimen, and offers advice and support

# PIH NOTE

When PIH started to work at the hospital site in Rwinkwavu, Rwanda, the buildings and other facilities were in complete disrepair, empty of equipment and medicines, and with few staff. Teams flew in to help from Zanmi Lasante (ZL), our sister organization in Haiti. As the ZL team worked with the Rwanda team, they described how things had been just as bad at the beginning of their work in Haiti—no buildings, no medicines, and people dying of preventable diseases. But, they insisted, things could and did get better; in fact, the ZL teams had transformed a hospital in Haiti into a functioning, welcoming environment that delivers a high standard of care to the poorest of patients. If they could do it, so, too, could the staff in Rwanda. Transforming experience into new action, the ZL team did more than just tell their story: they worked side by side with the team in Rwanda during the first few months to help their Rwandan counterparts establish new HIV/AIDS and TB programs.

### 3. ADVOCATING FOR THE COMMUNITY

It is vital that your advocacy work be rooted in the needs of the community. To do this, begin by learning who can help you identify these needs. Start by asking patients, families, and community leaders what the greatest needs of the community are. By providing space and modest funding for community members and patients to organize for change, you are showing your organization's commitment to helping the community.

### 3.1 Identifying community needs

Your patients can direct you to those in the community you should meet, both the elected formal leaders and the informal ones such as village chiefs, elders, and religious leaders. (See *Unit 1: Learning about the local context* for details about working with local leaders.) In visiting the local market and school, you will meet residents who will offer their views about changes they want to see in their community. Meeting with teachers at the local school can

provide insight about specific problems in families' and children's lives. Meeting with others who provide health care, particularly to the poor in rural communities, such as traditional birth attendants and traditional healers, is also valuable, as is listening to the voices of those in sports and other recreational groups.

### PIH NOTE

PIH works with Fonkoze, an organization in Haiti that advocates for very poor women through its program, Chemen Lavi Miyò, translated as "the Road to a Better Life". (See Unit 11: Addressing the social determinants of health through a program on economic and social rights (POSER) for more information about Fonkoze.) The women are selected by the communities, who identify the poorest, most vulnerable women in greatest need. The program provides assets and training to develop income-generating activities as well as training and support to improve their basic health care. Through creating these opportunities, Chemen Lavi Miyò aims to increase the members' self-confidence and self-esteem, empowering them to improve their lives and those of their families. Before entering the program, many of the women felt marginalized and ostracized by neighbors; as a result of their participation, many now feel respected, more integrated into community networks, and better able to look after their families. For one woman, "...She [my neighbor] no longer sees me as a beggar, but as a friend." For another, "The children used to go two days without eating anything, and then go beg food from next door. Now, since the program, I cook every single day for the children."<sup>1</sup> The initial pilot program reached 150 families. In the last few years, another 120 new families have participated, with the goal of extending the program to 5,000 ultra-poor families.

<sup>1</sup> Huda, K. & Simanowitz, A. (2008). Chemin Levi Miyò – midterm evaluation. Dublin: Concern Worldwide.

**TIP:** Join with those in the community who may already be engaged in advocacy, such as women's groups and associations of People Living with HIV/AIDS.

Each group will have its own perspective on how you can benefit the community, but many will wait and see how well your organization can deliver results that will benefit them. You may want to hold an open day for the local community. This day provides an opportunity to explain your plans and future projects and show local people how you work. Sharing a meal and interacting in this kind of informal setting allows the community to get to know you. You can also show your commitment to the community by contributing to its improvement outside of your normal work. In Rwanda, for example, where the government has established monthly



**Figure 6:** Traditional birth attendants training to become Maternal Mortality Reduction Program Assistants help connect their communities to the health clinic in Nkau, Lesotho

community work days, staff at the PIH-supported site, Inshuti Mu Buzima, joined the local community in repairing holes and digging trenches in the nearby road. Such local engagement can help you make sure that advocacy for policy change is as effective and locally relevant as possible. (See *Section 4, Advocating with policy makers.*)

# PIH NOTE

At the Bobete health center in Lesotho, staff identified one group in the community that had specific needs: young mothers in the 71 villages around the health center had high rates of HIV/AIDS and were at high risk for maternal mortality. These women had difficulty accessing medical care because they lived in remote villages separated from the health center by rough terrain. PIH staff met with the traditional birth attendants (TBAs)—local women who are part of Lesotho's traditional midwifery community—to ask how they could work together to address these problems. The result was a new and expanded maternal mortality reduction program that would also include continuing education for TBAs. PIH hired and trained 100 local women to serve as TBAs in an expanded role as community health workers who would provide a link between the center and pregnant women. Trained TBAs also ensured that the women received full access to the health center's services, including HIV testing and counseling, prevention of mother-to-child transmission of HIV/AIDS, pre- and postnatal care, and birthing facilities at the center. Traditionally, families pay TBAs for delivering babies; the new program provides TBAs with a cash incentive for each woman they accompany.

### 4. ADVOCATING WITH POLICY MAKERS

Advocating for patient rights and raising the standard of care in the wider community can be part of your daily work, embedded in your methods and your programs. How can these efforts be sustained in the long run? To encourage and achieve systemic change in policies and institutions, you will need the political support of local, district, and often national policy makers.

Your first task is to understand the political context: how decisions are made, and by whom. Ask for meetings with mayors or other local officials, and continue to meet with them on a regular basis. (See *Unit 1: Learning about the local context* for examples of how these officials can help.) Attending district-level planning and budget meetings provides you with opportunities to advocate for your work and to learn how the local officials interact with those in the national Ministry of Health (MOH).

The MOH is likely to be important to your operations in setting standards, procedures, and policies—from staffing to the programs you provide—so it is important to become familiar with the Ministry's current goals, policies, strategies, and future plans, and identify where your advocacy objectives can best fit. When you encounter gaps or policies that need to be updated or improved, consider how your objectives can contribute to the Ministry's goals and objectives and how you might help them make improvements in policies and move forward with their plans. Frequent contact with Ministry officials is key to furthering your case for change. As the Ministry is not a monolithic structure, you will need to have regular meetings with officials at local, district and (whenever possible) national levels; keep them up-to-date and informed. (See *Unit 10: Working with partners* for more details.)

**TIP:** Do a "mapping" exercise, a systematic listing of existing roles and responsibilities within the Ministry of Health at different levels. Mapping will help you identify what services are available and what is missing.

You can also use the informal contacts you have with your staff, community leaders, and other nongovernmental organizations (NGOs) in the area and country to identify which decision makers in the government, including the MOH, are likely to support you. When deciding how best to approach them, consider:

- Who are the key decision makers for specific policies at local/district/ national levels?
- When and where do they meet, and how can you participate?



**Figure 7:** Cutting the ribbon at the opening of the new Butaro District Hospital in Rwanda

- What are some acceptable ways to make your case? These might include written reports, requesting decision makers to visit the site, and calling on other contacts for their support.
- How might the timing of annual reviews and status reports help your conversations with policy makers?
- What are their budgetary and administrative constraints (and yours)?
- What are their potential conflicting interests?

### 5. USING EVIDENCE FOR ADVOCACY

Once you think through whom to approach and how your work might help those in government, you can develop specific ways to use evidence for such advocacy efforts. HIV/ AIDS activists have successfully used scientific evidence to influence policy makers and researchers to improve treatment for HIV-infected people. Other kinds of evidence that can also be used in successful advocacy for policy change include evidence that documents specific need, monitors impact, or demonstrates the benefits of a particular policy or approach to delivering health care. (Learn more about PIH's research activities in *Unit 13: Conducting research*.)

#### 5.1 Pilot programs

In your advocacy efforts with policy makers, build your case on the experience and evidence from your own programs. A pilot program is often a fruitful way to advocate for policy changes that impact both your organization and the Ministry of Health. This strategy can be attractive to Ministry officials because it provides them with proof that the change will be beneficial before they invest in a policy change that might meet with resistance or require substantial cost or disruption. Pilot programs can be vital tools in both small-scale improvements such as increasing medicine dosage at a single health center, and in advocacy efforts at the national scale-up of your larger successes. Pilot projects at all levels can help promote collaborative dialogue and minimize risk and fiscal waste.

### PIH NOTE

We work closely with ministries of health and follow their policies and treatment protocols, but there are times when we believe that a protocol change would benefit patients. At one site, we wanted to increase the Ministry protocol for a specific dosage of an HIV medication for pregnant women. We met with Ministry officials, explained our reasoning, and showed data that supported our approach. We suggested that our program might act as a pilot for this change at the national level, and we committed to keeping the Ministry closely informed of our results. The officials agreed and, once the changes were implemented, we met again and reviewed the outcome of the pilot. Working with the Ministry on this small-scale, low-risk trial basis helped us gain their trust and brought about a change in policy.

### 5.2 Disseminating evidence

As your programs grow, you may be able to document your evidence through formal publications and presentations. Healthcare workers can share findings through many different media, including hospital advocacy blogs and news reports, radio interviews, and healthcare journals for a range of different audiences. While you should also be collecting data for monitoring and evaluating your work, carrying out any type of research, analyzing results, and publishing them requires time, resources, and often additional staff that you may not have. (See *Unit 12: Using monitoring and* 



**Figure 8:** Staff from Socios En Salud join the procession in Lima, Peru during World TB Day *Photo: Socios En Salud* 

*evaluation for action.*) Media spotlights may be able to connect you with those who can help prepare your material for academic peer-reviewed publications. (See *Section 7, Using the media to advance key advocacy issues* in this unit.) Academic partners can be key in successful and timely publication of studies that demonstrate the impact of your programs on the health and welfare of the community. (See examples in *Unit 13: Conducting research.*)

Disseminating evidence that supports your work can increase opportunities to garner support for policy change with international as well as national policy makers. Others may

ask you to join them in a larger advocacy effort. For example, after PIH had documented in many studies the value of CHWs in delivering high-quality, community-based care,<sup>3</sup> PIH joined other international organizations and universities in a study about task shifting that was sponsored by the World Health Organization (WHO). The study focused on the role of CHWs in meeting the challenge of a catastrophic shortage of trained health personnel. When the researchers mapped out all HIV/AIDS-related tasks that took place at Haiti's Zanmi Lasante, they found a significant transfer of tasks from doctors to nurses to CHWs. The study also showed that when CHWs carried out these tasks, HIV/AIDS care and treatment rapidly become available to more patients with no apparent diminishment in quality of care. The final report on task shifting<sup>4</sup> uses this evidence to advocate for, among other things, the valuable contribution of CHWs in the health system. By showing their effectiveness, the findings also demonstrated the importance of paying them for their work.

**TIP:** Use many different methods to share your evidence with a variety of audiences. Community, policy, and healthcare experts can then apply it to make collaborative and practical improvements in healthcare delivery.

Evidence that documents your organization's effectiveness in achieving its stated goals is also an excellent advocacy tool to help you gain resources to support new policies and programs or ones that have been successful. The example of PIH in treating multidrug-resistant tuberculosis (MDR TB) in Peru in the *PIH Note* that follows is an example of how persistent advocacy based on evidence can make a difference.

<sup>&</sup>lt;sup>3</sup> See, for example, Mukherjee, J.S., Ivers, L., Leandre, F., Farmer, P. & Behforouz, H. (2006). Antiretroviral therapy in resource-poor settings: Decreasing barriers to access and promoting adherence. *Journal of Acquired Immune Deficiency Syndrome*, *43*(Suppl. 1):S123–26.

<sup>&</sup>lt;sup>4</sup> World Health Organization. (2007). *Task Shifting: Rational redistribution of tasks among health workforce teams: Global recommendations and guidelines.* Retrieved online at:*http://www.who.int/healthsystems/TTR-TaskShifting.pdf.* 

# PIH NOTE

In 1995, PIH applied to the Gates Foundation for a 10-year, multimillion-dollar grant to expand and document its treatment program for multidrug-resistant tuberculosis (MDR TB) in a vast, impoverished district of Lima, Peru, called Carabayllo. The research, carried out by PIH and our sister organization in Peru, Socios En Salud, showed that the 83 percent cure rate was attributable to our broad-based treatment approach, which "treats" physical, socioeconomic, and other aspects of the disease, including housing, employment, food, and moral support in addition to high-quality medical care.<sup>1</sup> The data proved that "untreatable" patients are in fact treatable and that this program would work. As a result, the dialogue was shifted away from an idea that MDR TB in the developing world was not treatable to the idea that it can indeed be treated and with good results. These findings led to action that overturned the conventional standard of care endorsed by the World Health Organization (WHO). The treatment program is now a replicable standard worldwide, which WHO recommends for even the poorest of countries. This experience illustrated the importance—and necessity—of creating changes within the large international bodies that set standards in financing and policy making.

<sup>1</sup> Mitnick, C. et al. (2003). Community based therapy for multidrug-resistant tuberculosis. *New England Journal of Medicine*, *348*(2):119–28.

### 6. COLLABORATING WITH OTHERS

If your organization is small and has limited resources, joining and working together with a network or coalition of other organizations can often bring results that are not possible for one program alone. Coalitions can vary: they can be permanent, with a designated staff and structure, or temporary, created for a specific goal and then disbanded. Some coalitions are area- or region-based, while others are organized around a single issue. Some coalitions are tightly structured, with purpose statements and



**Figure 9:** A conference to advocate for Haiti after the 2010 earthquake

formal membership, while others have loose transitional membership with a more flexible structure. Before you decide to join a particular network to help increase your advocacy, consider the following:

- Who is running the network/coalition, and what are its goals and objectives?
- What will your organization be expected to contribute?
- How can you ensure that you would have the time and resources to participate?
- What will be your organization's specific role in the network/coalition?
- How could your organization benefit?

You may find it most effective to identify specific staff—or create a subsection—in your organization that can concentrate on building collaborations to help advance advocacy efforts. In 1993, PIH established the Institute for Health and Social Justice (IHSJ) as an advocacy and policy arm to carry forward those policies that favor high-quality health care and social justice for the world's poor. Based at the PIH home office in Boston, the small IHSJ team focuses on developing and applying a rights-based framework to influence policy and U.S. legislation, and strengthening alliances within civil society that promote health and social justice on the basis of ethical and legal arguments about human rights for the world's poor. Because PIH does not have the capacity or resources to run large-scale advocacy campaigns, the team at the IHSJ concentrates much of its advocacy efforts on working with local, national, and international collaborators at PIH-supported sites.

# PIH NOTE

Through its research in Haiti, PIH demonstrated that targeted food assistance is associated with improved food security and that this assistance improves short-term quality of life for those people who live with HIV/AIDS.<sup>1</sup> One advocacy goal of this research was to generate evidence that would persuade policy makers and donors to fund a more long-term, integrated approach to food assistance. We decided that a conference would enable us to create a network of advocates for this approach. PIH and academic partners at Harvard University and at Tufts University's Friedman School of Nutrition Science and Policy cosponsored the 2007 conference, whose participants included representatives of international and national NGOs as well as nutritionists, agronomists, and donors.<sup>2</sup> When the conference ended, 15 groups and individuals signed a statement calling for changes in food policy for children under two years of age, access to adequate and nutritious food as part of the treatment package for poor people with HIV/AIDS and TB, and micronutrient supplementations in food assistance and agricultural planning. A year later, PIH worked with collaborators from the International Health Section of the American Public Health Association (APHA) to engage in advocacy efforts that targeted clinical policy makers. The result was a resolution on food security, subsequently adopted by the APHA, that called upon the U.S. government and international organizations to improve food security initiatives and strengthen food production and agriculture in developing countries. Such consensus documents have the potential to influence global policy changes with actions that began at the local level, by providing food to individuals.

If your organization is part of an NGO with headquarters in the United States, the U.S. Congress may draft legislation that can affect both the content of your programs and the resources you receive. If you are working on site in a remote area, it is unlikely you will be able to engage directly with policy makers in Washington, D.C. You can, however, collaborate with others who can advocate on your behalf. Before you engage in advocacy at

<sup>&</sup>lt;sup>1</sup> Ivers, L.C. et al. (2008). *Targeted food assistance improves food security and quality of life in people living with HIV in Haiti.* Abstract TUPE0663. XVII International AIDS Conference, Mexico City, Mexico. Retrieved online at: *http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200716383.* 

<sup>&</sup>lt;sup>2</sup> Partners In Health. (2007). *Integrating health, nutrition, and food security: Making the case.* Retrieved online at: *http://www.pih.org/pages/integrating-health-nutrition-and-food-security-making-the-case.* 

this level, it is vital that you understand the legislative process and that you are familiar with relevant legislative drafts and reports that relate to your concerns. There are several tasks that a group could undertake, even at a distance, to influence U.S. legislators:

- Identify those legislators who are engaged in your issues. Research biographies of Congressional members and their legislative aides, find out membership on committees and other bodies, and look up voting records.
- Be available to work on drafts of reports, declarations, or other documents that clearly express your concerns.
- Learn about how NGOs and concerned citizens lobby. If you want to engage directly in lobbying, discuss how you might build into your plan meetings with the legislators' staff and associates who do the daily work of drafting and implementing policy and law. Such persons are crucial in helping you reach policy makers and gain their support.
- Engage directly with legislators and their teams. Meet with them, send a high volume of emails, letters, and telephone calls, arguing your case.
- Follow up frequently with more meetings, emails, and telephone calls.
- Engage with the media to publicize the issue.<sup>5</sup>

# PIH NOTE

When our sister organization in Haiti, Zanmi Lasante, received early support from the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), funded under the former U.S. President George W. Bush, Zanmi Lasante used these funds to scale up care and treatment and of HIV/AIDS patients in Haiti, and documented its success in this endeavor. As a result, PIH was invited to participate in the Congressional hearings for PEPFAR's reauthorization, the legislation to renew its funding. We also worked with those drafting the reauthorization bill to make sure it included specific language that would support nutrition programs and the public sector.

### 7. USING THE MEDIA TO ADVANCE KEY ADVOCACY ISSUES

Research, expert collaboration, conferences or symposia, and participation in briefings and other meetings are all ways you can build advocacy and work toward national and international influence. Books, newspapers, radio, television, and the Internet can also help you direct your messages to reach a wider audience. These media help mobilize support from the general public, and even influence public opinion to exert pressure on policy makers.

<sup>&</sup>lt;sup>5</sup> For more advocacy tips on working with the U.S. Congress, see Results at: *http://www.results.org*.

**TIP:** Take advantage of important local events and national holidays to focus attention on your key advocacy issues.

#### 7.1 Live local media

Media does not always require technology such as film, print, or even electricity. You can get the message "live" to the community through real-time performers and entertainment at the local level. Songs, dance, and storytelling are often important communication tools in local communities, particularly in resourcepoor settings. Live local media may also narrate historical events that have shaped the community. You can use your contacts with teachers and with other community groups to learn about local storytellers and entertainers who can help you spread your message.



**Figure 10:** Traditional musicians and dancers celebrate in Rwanda

# PIH NOTE

PIH staff in Malawi launched "patient parties," a combination of social and educational activities for HIV/AIDS patients from all over Neno district. First, the staff talked with village headmen, whose acceptance was important for encouraging patients to attend. These monthly parties bring together hundreds of patients who can learn from each other how to cope with the daily challenges of living with HIV/AIDS. Activities also include features on how HIV/AIDS is transmitted and methods for preventing the spread of the disease, as well as entertainment by local music and dance groups. The parties have grown both in their importance to the community and in the number of attendees. At first only patients took part, but recent parties have drawn over 400 people, with local community members attending and learning first hand about the stigma and discrimination faced by those infected with HIV/AIDS. The parties are now organized and run by a committee of patients elected by their peers.

### 7.2 Mass media

#### 7.2.1 Opinion editorials

Opinion pieces are short essays that offer an educated opinion on an issue in a format intended to provoke discussion and promote change. They draw on facts, but they differ from evidence-based text in that they explicitly express the author's opinion. Newspaper and magazine editorials are usually opinion pieces. Newspaper and journal editors may also invite outside experts to submit editorials on specific issues. Advocacy groups sometimes hire skilled publicists to write an opinion editorial (op-ed). If you have writers in your program or community who have experience with the media, they may be able to help you write your own op-ed.

A formal op-ed is usually short (less than 700 words). Before writing it, you should first contact a newspaper, journal, or magazine that publishes opinion editorials to get their guidelines. Opeds are not simply opinions. In fact, the more stated opinions are backed by evidence, ideally from your organization, the more impact an op-ed is likely to have. Sometimes having the piece coauthored by someone who is well known and who shares your concern for the issue can increase the chances of getting it published. Co-authoring also provides a good opportunity to reach out to your



**Figure 11:** Using the media to make the case for 'building back better" in Haiti after the 2010 earthquake

partners, and presents readers with an example of groups working together on similar concerns.

**TIP:** Plan your opinion editorial to appear at the same time as a newsworthy event, such as the publication of a new report, or connect your theme to a special day, such as World AIDS Day or International Women's Day.

### 7.2.2 Letters to the editor

Most newspapers, magazines, and scholarly journals publish letters to the editor. Letters are usually shorter and more tightly focused than editorials and they allow publication of independent voices and views that need not agree with those of the editors. Letters give you another opportunity to present an opinion. They often respond to an article or another letter; they may correct misleading or erroneous information or address a current event or topic of interest. In order to make a difference, letters that respond to a particular claim or event must be written—and published—as soon as possible after the claim or event hits the news.

### 7.3 Preparing material for publications

Some organizations have a dedicated communications team. The PIH communications team prepares texts about the experiences of the programs at the sites, and publishes them in annual reports, brochures, and fact sheets that are distributed at conferences and other events. If it is not possible for your organization to dedicate one or more staff members solely to communications, you may be able to work with someone on your team or with an outside specialist who can write clearly and who knows your mission and goals well.

While some writers are also trained in basic text layout and design skills, keep in mind that professional layout and artwork is a separate specialty with skill sets that do not necessarily overlap with good writing. You will want to decide in advance how to divide such production tasks in your organization.

General tips for writing advocacy materials for publication include:

- Focus on one memorable message that is based on evidence from your work; avoid information overload.
- Present technical data using clear and ordinary words that your audience will understand and enjoy reading.
- Personalize your message by highlighting the success of patients or specific interventions.
- Keep the visual format simple; the photographs and other graphics that you choose to include will have the best effect on an uncluttered page.
- Budget costs before you start—and include production costs.

### 7.4 Websites and other electronic media

Websites and email groups (sometimes called listservs) can help you reach a larger audience than print materials alone. Electronic media can also be cheaper alternatives to print once you have covered the initial costs of setting up the website and various connections. Many Internet resources, including downloadable software, are open access, meaning that they are free to download and use. There are many resources available to help you recognize and respect copyright issues without undue complication.<sup>6</sup> Be aware, however, that even free electronic or digital resources have some costs, including those associated with maintaining the capacity and reliability of these systems. You can engage external help to design and set up a website, but there are many types of software available that a computer-literate staff member may be able to use to design and to maintain your website. Be careful to choose software that will be easy for your staff to use. Choosing simpler software that allows room for expansion can help you keep your time focused on the content of your message.

If your organization is still young or small and cannot initially attract traditional media attention, your own website, blog(s), and social media can help you spread your message. Social media, which is also low cost and sometimes free, has rapidly changed how we communicate. It is a particular publicity boon for those organizations, including nonprofits that operate on a shoestring budget. Whatever web-based platforms you use, update them with new content regularly—daily if possible.

An organization's website can be a powerful instrument for conveying its message and mobilizing a community. A dynamic and interactive website may include images, links, film, interactive web-based dialogue, and whatever other ingredients are important to your issues and your message. Local volunteers may have expertise to help you, or you may prefer to seek advice from professionals. Decide what audience you are writing for, whether

<sup>&</sup>lt;sup>6</sup> See, for example, Yamey, G. (2008). Excluding the poor from accessing biomedical literature: A rights violation that impedes global health. *Health and Human Rights: An International Journal*, *10*(1):21–42. Retrieved online at: *http://www.hhrjournal.org/index.php/hhr/article/view/20/103*.

it is health professionals, students, or the general public. This decision will shape how you design and communicate your message. If your audience is primarily the general public, you may want to concentrate on shorter pieces and quick facts. If you are writing to inform health professionals or knowledgeable lay people, you may want to post longer articles. General advice for structured writing includes:

- Focus first on communicating why the reader should care about this issue.
- Describe its impact and show how it affects people.
- Show what your organization is doing.
- Explain what readers can do.

As you plan your website, decide who will need to review the material and how much autonomy you will give to those producing it. The website is the "face" of your organization, so messages should be clear, consistent, timely, and relevant. Remember that too much administrative control can have a cost. A website that requires leaders' approval for every image or story may risk being out of date before it goes live, wasting space, time, and opportunity. If your staff is limited, have a clear approval process and chain of command that consists of those who can both collaborate and act independently on a shared vision. The review process should be defined from the start, with clear procedures to ensure this happens in a timely manner even as staffing changes.

### 8. BUILDING A MOVEMENT

While local and regional collaboration is an effective tool for advancing your advocacy efforts, you may want to be part of a larger, longer-term effort that shares your vision to improve the state of the world's health. One option is to join a network of individuals and organizations from community, national, and international levels all around the world. For

example, the People's Health Movement is a loose network of like-minded activists and health professionals who hold meetings and exchanges and engage in international and national campaigns to advocate for access to primary health care for all.<sup>7</sup> Networks like these can help keep you informed of others' advocacy, and at the same time include you as part of its broader movement for change.

Over many years PIH has tried to cultivate a network of supporters who understand our work and help to expand it in order to encourage and advance a movement for social justice and highquality health care for the poor. (For more



**Figure 12:** A group of women in rural Malawi fight the HIV/AIDS epidemic in their village by raising awareness about the disease

<sup>&</sup>lt;sup>7</sup> See Turiano, L. & Smith, L. (2008). The catalytic synergy of health and human rights: The People's Health Movement and the Right to Health and Health Care campaign. *Health and Human Rights: An International Journal, 10*(1):137–47. Retrieved online at: *http://www.hhrjournal.org/index.php/hhr/article/view/31/116*.

details about building this movement, see *Unit 9: Creating a development strategy* and *Unit 10: Working with partners.*) PIH hosts an annual public event in Boston, the Thomas J. White Symposium, as a time for reflection on the work of the past year, and to share insights into how the organization's mission has been carried out. You may also wish to initiate similar events, gathering staff to exchange ideas and to reconnect with supporters. Through such regular happenings, an organization can aim to encourage those who support its work to continue their efforts and to inspire others to join.

# PIH NOTE

By 2009, extraordinary levels of global funding for HIV/AIDS and multidrug-resistant tuberculosis (MDR TB) treatment were causing widespread criticism that such disease-specific initiatives ran counter to the importance of integrated primary health care, especially in resource-poor settings. To address and move beyond this tension, PIH hosted a two-day meeting that was attended by a variety of global health constituencies from the United States, Europe, Latin America, and Africa. Advocates for HIV/AIDS, TB, primary health care, sexual and reproductive rights, women's health, and child health all met to craft a joint strategy for activism based on the right to health. They defined this right as a right to preventive and curative care, anchored in and coordinated by the public sector and delivered to all regardless of ability to pay. PIH drafted a background paper, Bridging the Gap,<sup>1</sup> to ensure that the focus of the meeting would be clear. We encouraged consensus by discussing the paper and the meeting's aims beforehand with many of the participants. The result was a shared vision—a declaration calling for solidarity in the global health community to achieve the right to health for all persons. The declaration<sup>2</sup> is one example of an advocacy document; the fact that it was signed by 1555 individuals and 303 organizations representing 96 countries suggests its potential to influence primary healthcare strengthening efforts around the world.

#### 8.1 Student groups

Attracting students and young people can help build long-term supporters. Young people's energy, creativity, and extensive social links have helped many groups take a lead in advocating for global health and social justice. GlobeMed, which partners with grassroots organizations to address health inequalities, has chapters in universities and colleges across the United States. Another group, FACE



**Figure 10:** During their 67-day ride, a FACE AIDS team spoke about HIV/AIDS prevention and raised funds to support PIH's work in Rwanda

<sup>&</sup>lt;sup>1</sup> Partners In Health. (2009). *Bridging the gap*. Retrieved online at: *http://parthealth.3cdn.net/8bc57559f82d715461* \_*lum6bn5df.pdf*.

<sup>&</sup>lt;sup>2</sup> Partners In Health. (2009). *Declaration of solidarity for a unified movement for the right to health*. Boston, MA: Partners In Health. Retrieved online at: *http://act.pih.org/page/-/Declaration\_of\_Solidarity.pdf*.

AIDS, provides young people with skills and resources to fight HIV/AIDS and promote global health equity. The Global Health Corps provides year-long fellowships that recruit, train, and support young professionals from diverse backgrounds to work for global health equity. Many of these groups also provide fundraising opportunities that help support organizations in resource-poor countries. For more information on partnering with students and other groups of young people, see *Unit 10: Working with partners*.

**TIP:** Start an email group, listserv, or online group for students and young people, with news about upcoming events and how readers can contribute.

### 8.2 Internship programs

Internship programs for students and young professionals interested in health and social justice issues can further fuel advocacy efforts and social justice movements, especially as they pertain to developing countries. PIH summer interns work on projects that link their interests with the organization's programmatic needs. Interns also attend lectures and events and learn about all aspects of the work and that of our partners. Many of these interns later go on to careers with other NGOs, local service and health agencies, or to pursue degrees in medicine and public health. Keeping in touch with the interns after their summer experience and helping them stay in contact with each other further builds the movement for health and social justice. Another way to harness the interest and energy of young people as well as increase your group of supporters is to run a volunteer program; see *Unit 10: Working with partners* for details on how to establish and maintain a successful volunteer program.

When speaking with students and young people, you can suggest activities that they might put into action immediately. These might include contacting local politicians, organizing fundraising events, or gathering news updates about global health issues that are relevant to your organization. For example, the Health and Social Justice Video Network, launched by PIH, distributes videos online that can inform and inspire a growing movement for health and social justice. The Network has a live-streaming component so viewers can participate in online events in "real time" from wherever they are. Meeting electronically reduces costs and equalizes participation by ensuring that anyone around the world who has Internet access can attend.

### CONCLUSION

As a program manager, you are in an important position to encourage advocacy efforts for your patients, your staff, and your local and national community. Your patients will value the opportunity to voice their needs and concerns in constructive tools for action. Advocacy helps healthcare staff to envision and realize a human rights-based environment where they can flourish as they get training and provide care. Using program evidence to advocate for healthcare delivery improvements with policy makers increases your ability to shape local, regional, and national health policies and practices. Collaborative partnerships with other organizations can help you address and minimize barriers that may result from competition over available resources. Local storytellers, community artists, and writers can give zest to your media messages for change. All these advocacy efforts can treat new and existing challenges as opportunities to build a movement for health.



**Figure 14:** The design for the Mirebalais complex, the first public, national referral in Haiti health facility



**Figure 15:** Building the new teaching hospital in Mirebalais, Haiti

### PIH NOTE

"Building Back Better"—PIH's advocacy to rebuild Haiti—highlights many of the advocacy tools described in this unit. During the first three months after Haiti's earthquake in January 2010, we focused our advocacy efforts to "Build Back Better" with our collaborators on the rights of the Haitian people and government to rebuild their country and on improved use of emergency and long-term development aid for Haiti. With collaborators, we developed a rights-based framework that would help ensure accountability and transparency for donors, implementers, and NGOs on the basis of ethical and legal rights to health for poor persons in need. To further our appeal for a rightsbased approach to aid for Haiti, we held individual meetings with members of the U.S. Congress, participated in briefings and panels, and continued to advocate for maximum funds for reconstruction from the U.S. government as well as new implementation policies and programs. At the local level, we followed through on a series of advocacy activities in partnership with our sister organization, Zanmi Lasante, and the Haitian Ministry of Health to put into action the idea of "building back better." Construction on an innovative 320-bed teaching hospital in Mirebalais, Haiti, planned since 2008 as a national referral facility, began soon after the earthquake. Once complete, the hospital will offer clinical facilities not available at any other public site in the country, with partnerships with leading universities and teaching hospitals as well as visiting clinicians to help train Haitian clinicians and further advocacy efforts to improve health in this resource-poor setting.



### Resources

#### WORKS CITED

Behforouz, H. (2009, December 21). Health reform lessons, via Haiti and Peru. *Boston Globe*.

Government of Rwanda. (2007, November). *Rwanda rural health care model: A comprehensive approach to rural health*. Kigali: Government of Rwanda.

Ivers, L.C. et al. (2008, August). Targeted food assistance improves food security and quality of life in people living with HIV in Haiti. Abstract TUPEO663. XVII International AIDS Conference, Mexico City, Mexico. http://www.iasociety.org/Default.aspx?pageId=11&abstractId=200716383

Huda, K. & Simanowitz, A. (2008). Chemin Levi Miyò – midterm evaluation. Dublin: Concern Worldwide.

Mitnick, C. et al. (2003). Community based therapy for multidrug-resistant tuberculosis. *New England Journal of Medicine*, 348(2):119–28.

Mukherjee, J.S., Ivers, L., Leandre, F., Farmer, P. & Behforouz, H. et al. (2006). Antiretroviral therapy in resource-poor settings: Decreasing barriers to access and promoting adherence. *Journal of Acquired Immune Deficiency Syndrome*, 43(Suppl.1):S123–6.

Mukherjee, J.S., Eustache, E., Oswald, C., Surkan, P.J., Ermaze, L., Scanlan, F., Wong, R., Li, M., Leung, L., Smith Fawzi, M.K. (2010). *Standing up for our rights—an intervention that promoted HIV-positive caregivers and their children to plan for their future and play a more active role in their community.* Poster presented at the XVIII International AIDS Society conference, Vienna, Austria.

Partners In Health. (2007). Integrating health, nutrition, and food security: Making the case.

http://www.pih.org/pages/integration-health-nutrition-and-food-security-making-the-case

Partners In Health. (2009). Bridging the gap. http://parthealth.3cdn.net/8bc57559f82d715461\_lum6bn5df.pdf

Partners In Health. (2009). Declaration of solidarity for a unified movement for the right to health. Boston, MA: Partners In Health. http://act.pih.org/page/-/Declaration\_of\_Solidarity.pdf Turiano, L. & Smith, L. (2008). The catalytic synergy of health and human rights: The People's Health Movement and the Right to Health and Health Care campaign. *Health and Human Rights: An International Journal, 10*(1):137–47. *http://www.hhrjournal.org/index.php/hhr/article/view/31/116* 

United Nations Office of the High Commission for Human Rights. (1948). Universal declaration of human rights. http://www.ohchr.org/EN/UDHR/Pages/Language.aspx?LangID=eng

World Health Organization. (2007). Task shifting: Rational redistribution of tasks among health workforce teams: Global recommendations and guidelines. http://www.who.int/healthsystems/TTR-TaskShifting.pdf

Yamey, G. (2008). Excluding the poor from accessing biomedical literature: A rights violation that impedes global health. *Health and Human Rights: An International Journal, 10*(1):21–42.

http://www.hhrjournal.org/index.php/hhr/article/view/20/103

Zanmi Lasante/Partners In Health. (2001). *The declaration of Cange: World AIDS Day* 2001.

http://www.pih.org/publications/entry/the-declaration-of-cange-world-aids-day-2001

#### SELECTED RESOURCES

#### **Goals and Objectives**

Bobo, K., Kendall, J., & Max, S. (2010). **Organizing for social change: Midwest Academy Manual for Activists.** 4th ed. Chicago, IL: Midwest Academy. This handbook teaches the fundamentals of direct action organizing, through a systematic approach to the techniques of organizing, building, and using power to create lasting institutions for advocacy.

### Pelton, E. & Sprechmann, S. (2001). Advocacy tools and guidelines: Promoting policy change. Atlanta, GA: CARE.

#### http://www.care.org/getinvolved/advocacy/tools.asp

This is a step-by-step guide for planning and implementing advocacy initiatives. The guidelines help readers learn about advocacy concepts and vocabulary, analyze policies, and devise a strategy to achieve advocacy aims. It suggests a framework for identifying policy goals, creating a plan of action, and building a case for change.

#### **Advocating for Patients**

Huda, K. & Simanowitz, A. (2008). Chemin Levi Miyò – midterm evaluation. Dublin: Concern Worldwide.

This evaluation assesses the effectiveness of the Fonkoze project, Chemen Lavi Miyò, to improve the lives of the poorest women in Haiti, and the challenges it faces. It looks at early indicators of progress, including the targeting of the very poor through the community participatory wealth ranking system, and five other areas: enterprise development and training, capital investment, social development, essential health care, and microcredit.

### Mukherjee, J. & Eustache, Fr. E. (2007). Community health workers as a cornerstone for integrating HIV and primary healthcare. *AIDS Care*, *19*(1):S73–S82.

http://www.givewell.org/files/Round2Apps/Cause1/Partners%20In%20Health/B/AIDS%20Care%20Paper%20-%20Mukherjee%20and%20Eustache.pdf

This paper presents the background to the expansion of a community-based HIV/AIDS prevention, care, and treatment model to public health clinics across central Haiti. In this model HIV/AIDS services are closely linked to, and integrated into, primary health services; and community health workers provide medical treatment, emotional support to people living with HIV/AIDS, and education on HIV/AIDS prevention to the community.

Mukherjee, J.S., Ivers, L., Leandre, F., Farmer, P. & Behforouz, H. (2006). Antiretroviral therapy in resource-poor settings: Decreasing barriers to access and promoting adherence. *Journal of Acquired Immune Deficiency Syndrome*, 43(Suppl.1):S123–6.

The article describes the impact of including these four components in HIV/AIDS treatment: (1) free health services and medication (2) integration of HIV/AIDS testing, treatment, and care into primary health care (3) a monthly transportation stipend for routine clinic and emergency visits, and food subsidies for the neediest patients (4) use of community health workers.

#### **Advocating with Policy Makers**

Porter, R.D. & Hicks, I. (1995). **Knowledge utilization and the process of policy formation: toward a framework for Africa.** Washington, D.C.: Support for Analysis and Research in Africa (SARA) & Academy for Educational Development (AED). *http://sara.aed.org/publications/cross\_cutting/knowledge\_utilization/html/ utilization.htm* 

This paper reviews the published literature on the role of technical information in the making of public policy, examines more general models of the policy process, and outlines a framework for rethinking the relationship between policy research and advocacy.

Sharma, R. (1997). **An introduction to advocacy: Training guide.** Washington, D.C.: Support for Analysis and Research in Africa (SARA) & Academy for Educational Development (AED).

http://www.globalhealthcommunication.org/tool\_docs/15/an\_introduction\_to \_advocacy\_-\_training\_guide\_%28full\_document%29.pdf

Written primarily for use in training sessions, this guide aims to build basic advocacy skills, increase the use of available data to inform the advocacy process, and help readers plan a particular advocacy campaign.

### World Health Organization. (2007). **Networking for policy change: TB/HIV** advocacy training manual. Geneva: World Health Organization.

*http://www.stoptb.org/assets/documents/countries/acsm/Final%20Manual\_edited.pdf* This training manual was prepared to help NGOs and other civil society groups to form and maintain advocacy networks and develop effective TB/HIV advocacy skills. It includes information on networking, communications, and policy environments; and exercises on conceptualizing, implementing, monitoring, and evaluating advocacy campaigns.

#### Collaborating with Others

### RESULTS

#### http://www.results.org/

This is the website of a nonprofit organization which focuses on changing U.S. legislative policy and increasing public awareness about ending poverty. The "Skills Center" section provides information about to how to start and grow a RESULTS group, advocacy and fundraising tips, outreach materials, and links to external resources.

#### Building a Movement

### Partners In Health. (2007, October). Integrating health, nutrition, and food security: Making the case.

*http://www.pih.org/pages/integrating-health-nutrition-and-food-security-making-the-case* This meeting brought together groups working on health, food systems, agricultural development, and nutritional programs to develop recommendations for policies that can break the cycle of food insecurity, malnutrition, and ill health. The website provides access to presentations from the conference and the Conference Statement developed by Partners In Health and 15 other organizations and individuals.

#### Partners In Health. (2009). Bridging the gap.

#### http://parthealth.3cdn.net/8bc57559f82d715461\_lum6bn5df.pdf

This is the background paper of the 2009 conference that aimed to develop a joint strategy for activism: to advocate for the right to health, both preventive and curative care based in the public sector and accessible to all, regardless of the ability to pay. The website also contains additional reading materials.

### Partners In Health. (2009). **Declaration of solidarity for a unified movement for the right to health.** Boston, MA: Partners In Health.

http://act.pih.org/page/-/Declaration\_of\_Solidarity.pdf

The Declaration describes the context from which the declaration arose and the importance of activism to achieve global health equity and social justice. It serves as the backbone of PIH's advocacy agenda.

### Turiano, L. & Smith, L. (2008). The catalytic synergy of health and human rights: The People's Health Movement and the Right to Health and Health Care

**campaign.** Health and Human Rights: An International Journal, 10(1):137–47. http://www.hhrjournal.org/index.php/hhr/article/view/31/116

The article discusses how the response of the People's Health Movement and its Right to Health and Health Care Campaign have been influenced by several concerns: the failure to implement the primary health care strategy defined in the Alma Ata declaration, the discipline of social medicine, and the application of human rights methods to local health problems and to organizational practice.

#### **Tools for Student Groups**

### FACE AIDS

#### http://faceaids.org/mission.html

Started in 2005 by students at Stanford University, FACE AIDS is building a movement for global health equity and social justice, and is present in more than 210 colleges and high schools in the U.S. and 30 chapters in Rwanda. The website provides information about the youth movement and joining a chapter, the socioeconomic support they offer to patients, their summer fellowship program, and ways to join advocacy efforts.

### **Global Health Corps**

### http://www.ghcorps.org/

This is the website of Global Health Corps, who work to build a global movement toward health and social justice by recruiting, training, and supporting future leaders and by diversifying the pool of young people working in global health. They provide year-long fellowships for college graduates; each fellowship team is composed of at least one fellow from the U.S. and one from the country where the partner organization works.

### GlobeMed

### http://www.globemed.org/

This is an organization that has developed a comprehensive set of programs to educate, enable, and inspire students. It provides an online manual of tools and resources, and also includes information on developing partnerships, organizing fundraising events, and working with universities.

#### **Partners In Health**

#### http://www.pih.org/

The "What You Can Do" section of the Partners In Health (PIH) website presents information about connecting with PIH (including the summer internship program), joining an activist organization, organizing an event, and links to recommended reading about advocating for global health equity.