Neglected Tropical Disease Control Program

Advocacy Guide for Sustainability: Generating In-Country Support For Integrated NTD Control

December 2009

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Networking for Policy Change: TB/HIV Advocacy Training Manual. StopTB Partnership, World Health Organization (WHO), and Constella Futures. January 2007.

Fundraising and Advocacy Toolkit. Global Alliance to Eliminate Lymphatic Filariasis. 2005.

Roll Back Malaria Advocacy Guide. Roll Back Malaria/World Health Organization. 2000.

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Abbreviations

ECOWAS	Economic Community of West African States
IEC	Information, education, and communication
LF	lymphatic filariasis
MDA	mass drug administration
MOE	Ministry of Education
MOH	Ministry of Health
NGO	nongovernmental organization
NTD	Neglected Tropical Disease
STH	soil-transmitted helminths
UNICEF	United Nations Children's Fund
USG	United States Government
WHO	World Health Organization

Introduction

Why This Manual?

The purpose of this manual is to provide partners with the resources they need to successfully advocate on behalf of the Neglected Tropical Disease (NTD) Control programs in the countries where these diseases are endemic. Partners will learn how to effectively raise awareness about NTDs within the general population and among key influential people to garner sustained ownership, leadership, and commitment from governments and their partners for programs aiming to eliminate or control these diseases.

What Is Included?

1. **Background: The Context for NTD Advocacy**

   A section on a common understanding and framework for NTD advocacy

   - Definition of advocacy
   - Overarching goals for NTD advocacy
   - Common/global messages for NTD advocacy

2. **Developing an Effective NTD Advocacy Plan**

   "How To" Section—Developing and Monitoring an Effective In-Country NTD Advocacy Strategy

   - What do you want to accomplish?
   - Who do you need to target?
   - Building coalitions
   - Identifying champions
   - Communicating effectively
   - Evaluating your advocacy efforts

3. **Tools and Resources: Handouts and Guides to Support Implementation**

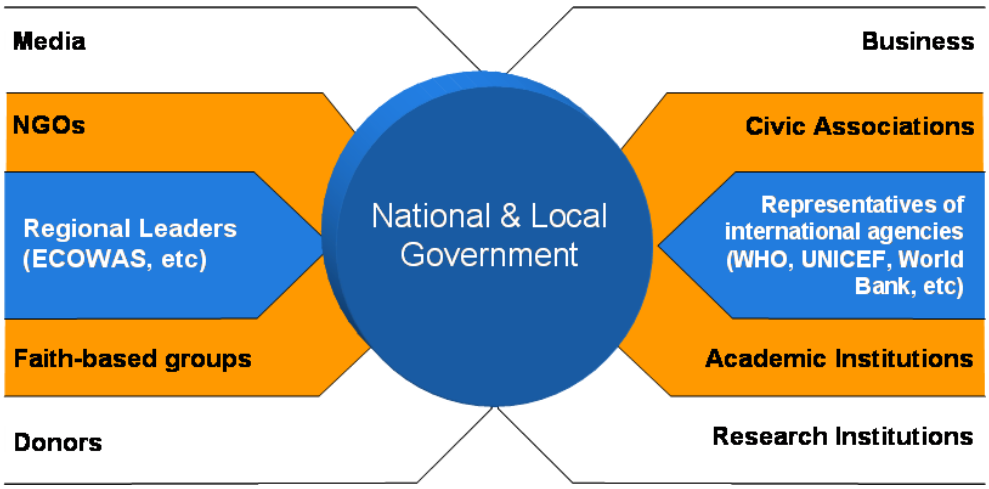
I. Background: The Context for NTD Advocacy

1. What is Advocacy?

Advocacy is the pursuit of influencing policies and spending by gaining the support of key stakeholders in a country. The general goal of advocacy efforts is to bring about positive outcomes in communities confronted by issues that can be addressed through increased awareness and support.

This toolkit provides guidance and resources for in-country advocacy in support of NTD control programs. The desired outcome of in-country advocacy efforts is to increase government commitment for integrated NTD control strategies so that sustainability of these programs can be assured beyond the availability of external resources. Your advocacy plans should therefore focus primarily on building support at the government level. As **Figure 1** (below) demonstrates, however, there are multiple "pressure points" for getting your message heard by the government; this toolkit will help you determine which are the most important and accessible pressure points in your country so that you can develop a successful advocacy plan.

Figure 1: Pathways to Building Support at the Government Level



Advocacy activities should be selected and adapted based on the situation in your country. There is no one way to carry out effective advocacy. Rather, this toolkit will guide you through the process of developing a systematic, country-specific advocacy plan.

An important distinction to note is the difference between advocacy and other related communication efforts, including information, education, and communication (IEC), public relations, and community mobilization. As noted in **Table 1** (below), the target audiences, objectives, and measures of success are different for these three different strategies. While acknowledging the importance of all three strategies in developing a successful NTD program, this toolkit focuses solely on the strategy of advocacy to seek increased government commitment to favorable NTD policies and resource allocation.

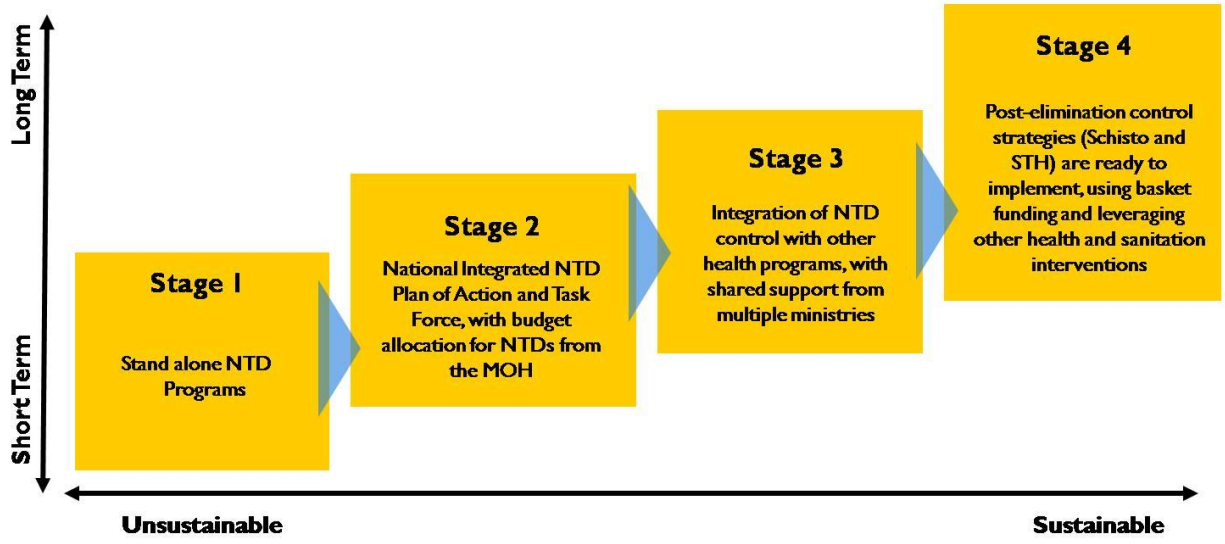
Table 1: Differentiating Advocacy from other Communication Efforts

Strategy	Target Audience	Objective	Measures of Success
IEC	Endemic populations	Behavior change and awareness raising	Increased mass drug administration (MDA) coverage and compliance; increased morbidity management, etc.
Community mobilization	Community members and local leaders	Capacity building at the community level	Increased community participation, increased demand for MDA, and improved compliance
Advocacy	Policy makers	Influence policies and allocation of resources	Budget line item for NTDs; new policy commitments, etc.

2. Overarching Goals for NTD Advocacy

The primary vision of NTD control efforts is reaching long-term sustainability of NTD programs, as demonstrated in **Figure 2** (below).

Figure 2: The Continuum of Sustainability



The overarching goals for in-country NTD advocacy are as follows:

- Creating **awareness** of strategies for NTD control, **demand** for integrated control programs, and **sustainable resource streams** for the elimination or control of NTDs at the government level.
- **Increasing capacity** of all partners—public and private—to be effective advocates for integrated NTD control and elimination.
- **Forging alliances** beyond the NTD community to expand the efficacy and cost-efficiency of NTD control and elimination, with the long-term vision of communities and countries where NTD control is an accepted, integral part of primary public health services.

3. Common Messages for NTD Advocacy

The NTDs

- Intestinal parasites (soil-transmitted helminths, [STH])
- Elephantiasis (lymphatic filariasis, [LF])
- River blindness (onchocerciasis)
- Snail fever (schistosomiasis)
- Trachoma

What Is Their Collective Impact?

- Are endemic in over 100 of the poorest countries in Africa, Asia, and Latin America—most often with multiple diseases affecting the same communities
- Infect more than 1 billion people (one or more of these disabling diseases)
- Exacerbate poverty by requiring tremendous costs for medical treatments and physical incapacitation, thus decreasing school attendance and negatively affecting livelihoods

Why Is an Integrated Treatment Approach Effective?

- Low-cost and effective tools exist to control or eliminate the diseases through annual community-based treatments
- Effective public-private partnerships to provide support at local, national, and international levels (the World Health Organization [WHO], World Bank, nongovernmental organizations [NGOs], the U.S. Agency for International Development [USAID], and other development assistance agencies, multinational corporations, religious and civic groups, etc.)
- Drug donations from GlaxoSmithKline, Johnson & Johnson, Merck, Merck KGaA, and Pfizer

- Global efforts are working toward
  - increased human capacity development, because health workers and volunteers are trained in social mobilization techniques, health education, and treatments that have much in common
  - greater human resource and cost efficiencies, because the same delivery systems and workers can be used for multiple interventions
  - more positive impact on the health of affected communities

What is the Impact of NTD Control on the Millennium Development Goals?

- **Goal 1: Ending Poverty**. The socioeconomic impact of eliminating and controlling debilitating NTDs is estimated to be enormous as a result of saving money on medical costs and increasing productivity.
- **Goal 2: Universal Education**. Disease and poverty form a vicious cycle leads to reduced school attendance. Preventing and treating NTDs in children improves cognitive development, growth, and school attendance.
- **Goal 4: Reducing Child Mortality**. Children affected by NTDs are more vulnerable to life-threatening health problems like malaria and severe anemia.
- **Goal 5: Improve Maternal Health**. Preventing NTDs leads to decreased rates of severe maternal anemia, malaria, and HIV.
- **Goal 6**: **Combat HIV/AIDS, Malaria, and Other Diseases**. NTDs are part of the "other diseases" targeted for reduced incidence by 2015.

II. Developing an Effective NTD Advocacy Plan

1. Establishing Country-Specific Objectives

Identifying Key Issues

The first step to an effective advocacy campaign is to identify the main issues confronting NTD control programs in your country *that can be addressed through policy change*. These issues will vary by country based on many factors. In identifying the key issues surrounding NTD programs in your country, it is important to include a variety of relevant parties involved in NTD implementation in determining the most important issues confronting their NTD work.

Examples of key issues include

- Inadequate funding for NTD program implementation
- Lack of commitment within the Ministry of Health (MOH) to control of NTDs
- Lack of commitment in MOH for integrating disease-specific NTD control programs
- Lack of government funding for one or more of the NTD programs

Developing Policy Solutions

Note that each of the example key issues listed above has a possible policy solution. For each of the key issues you identify for your country, you must also determine how the government can help solve this problem.

Exercise 1

Through examinations of your data and conversations with relevant NTD stakeholders in your country, carry out the following exercises:

1) Identify three issues confronting NTD programs in your country that require policy action.
2) For each issue, list at least one policy solution.

Creating an Advocacy Objective

Using the key issues that you have just identified for policy action and their corresponding solutions, you will now develop an advocacy objective. The following factors are important when choosing this objective:

- Political climate
- Money available to support your advocacy efforts
- Your organization's capacities
- The capacities of partner organizations

Remember that focusing your advocacy efforts on just one or two objectives is typically more effective and achievable than trying to do too much.

The first step is to identify your country-specific advocacy **goal**. Goals are typically the longer-term vision of what your organization would like to achieve. For NTDs, an example of an advocacy goal could be: *"Control or eliminate NTDs in our country through integrated implementation of NTD mass drug administration."*

Exercise 2

What is the goal of your organization's efforts that you hope to support through advocacy? What do you want to achieve in the next 10 years? In the next 20 years?

The next step is to develop your advocacy **objective**. Objectives are shorter-term than goals, are more specific, and must be measureable. Consider the following questions when developing your advocacy objective:

- ***What*** do you want to change through advocacy?
- ***Who*** will make the change?
- ***How much*** change will be achieved?
- ***When*** is the deadline for the change to be accomplished?

Examples of advocacy objectives for NTDs are: "In the next 2 years, increase government funding for the NTD programs by 75%" or "Achieve the creation of a government budget line for NTD integration financing within the next 12 months."

Exercise 3

Develop a specific and measurable advocacy objective identifying what you want to change, who is responsible for making the change, how much change you expect, and when you will accomplish the change.

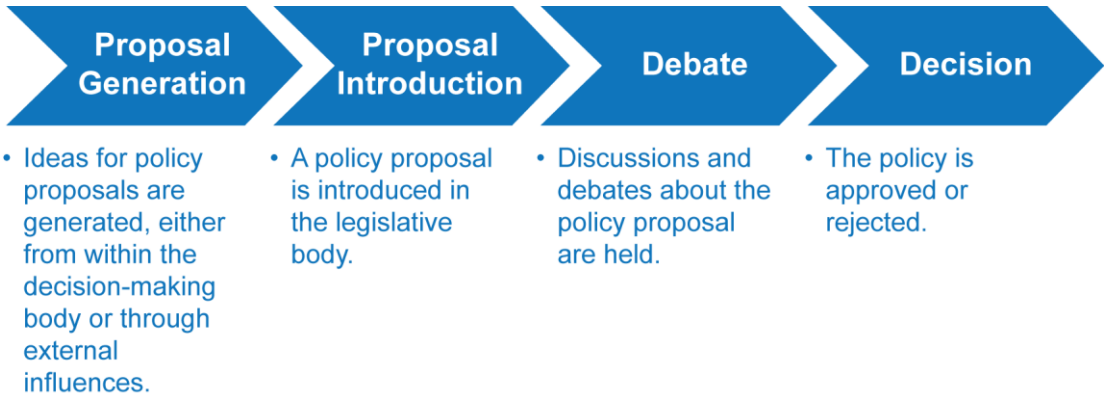
Please complete worksheet on page 39.

2. Identifying Country-Specific Target Audiences

Understanding the Policy Process

Although there are some common elements in the policy process across countries, every country will have its own unique structure with different rules and procedures for decision making. Most governing bodies incorporate the general steps in **Figure 3** in their policy process.

Figure 3: The Policy Process



If a policy is approved, it is either moved to the next level of decision making or implemented. If a policy is rejected, it may return to a previous stage for revision.

In addition to the formal policy process, which is the official legal procedure illustrated above, there is an **informal process**, which is composed of activities and procedures that often take place in parallel to the formal process. During this informal process, there is an opportunity for NTD experts to raise awareness of the programs and educate policy makers to influence the formal policy process.

Exercise 4

Identify the policy process for target institutions by answering the following questions:

1) What institution is responsible for making the decisions that you are trying to influence through advocacy?
2) What are the steps of the decision-making process for that institution? What is the timeline for these steps?
3) Where are there access points in the informal policy process?
4) Who are the key power holders at each step of the decision-making process?
5) At what points during this decision-making process will you be able to influence the key power holders?

Please complete worksheet on page 40.

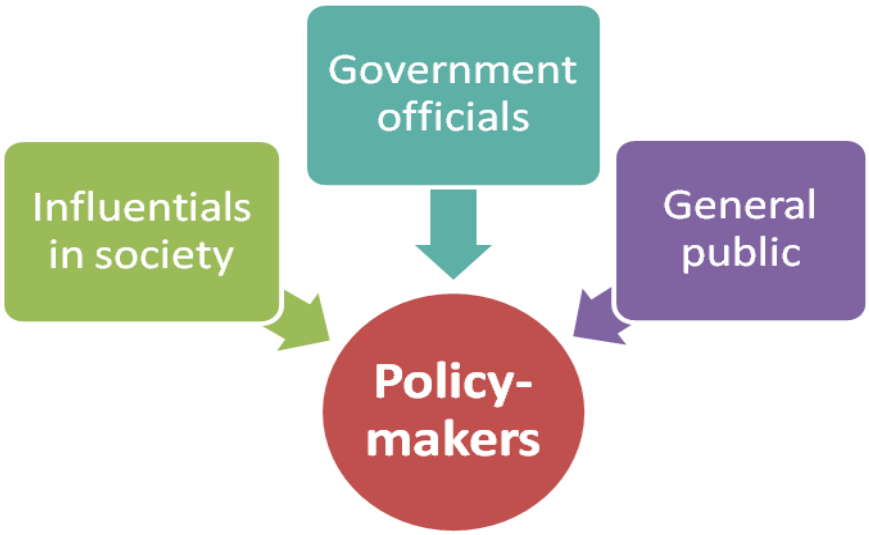
Policy Audience Overview

Policy audiences can be divided into **primary** and **secondary** audiences.

The **Primary Audience** is the main target of your advocacy strategies. For the purposes of this toolkit, the primary audience is made up of the decision makers and other power holders who can directly determine whether your objective is successful or not. It may be difficult to access these individuals directly, so it is useful to also target a secondary audience.

The **Secondary Audience** is composed of any groups or individuals that can help you to influence your primary audience. Sometimes high-level officials can influence other decision makers and are therefore part of the secondary audience. Examples of secondary audiences are included in **Figure 4.**

Figure 4: Policy Audiences



It is therefore important for your advocacy strategy to reach multiple audiences. You should keep in mind, however, that your efforts should directly target either the policy makers or those who can influence the policy makers to impact the decision-making process.

Please complete worksheet on page 41.

Targeting Decision Makers and Influential People

Since your advocacy objective involves the need for policy change at the government level, the main focus of your advocacy activities should be reaching out to policy makers and the groups of people who influence them. Included in this group of influential people are policy makers, ministry officials, influential organization leaders (such as representatives from WHO's country office), and celebrities who can access high-level officials.

Target groups will vary by country and will be based on the advocacy objective that you are pursuing. For example, if the NTD package for which you are advocating includes school-based interventions such as treatments for STH and schistosomiasis, then it will likely be important to target the Ministry of Education (MOE) in your advocacy efforts. If, however, your country's NTD package contains only community-based interventions, then targeting the MOE may not be as important as focusing on the MOH and other officials.

Targeting the General Public

The general public can be effective at working toward policy change, so it is important for the public to be kept well-informed about NTD programs and the importance of NTD treatments to the health of their communities.

When members of the general public work together to raise awareness for an issue, they are carrying out "grassroots advocacy." Policy makers listen when a clear and simple message is being reinforced by large numbers of their constituencies.

This population can be further split into two groups.

- **Endemic communities.** Populations living in endemic communities are typically rural and poor, making them the most difficult group to reach. As a result, NTD programs have created important social mobilization tools to raise awareness about the importance of MDAs and methods of controlling NTDs. *(As indicated in Section 1, social mobilization is a separate activity than advocacy. Strategies for developing these important tools are outside the scope of this toolkit but are vital for the successful implementation of NTD interventions.)*

  Though these communities have little influence in politics, their involvement in advocating for the need of NTD treatments in their communities can be highly impactful. First, endemic communities can be mobilized to create demand for NTD services, which may cause the government to become more involved in ensuring that the services are available. Additionally, patients suffering from an NTD infection who are willing to share their experiences can provide compelling first-hand accounts of how the NTDs have affected

their lives. These life stories are often extremely effective at demonstrating the importance of NTD programs and persuading policy makers to support these programs.

- **Non-endemic communities.** Although some areas of the country may not suffer from NTDs directly, people living in non-endemic communities may have friends or family members living in endemic areas and have seen the devastating impact of the NTDs. The general public should be informed of the ways in which they can get involved in raising support and awareness of the NTD programs that are helping people in their communities.

3. Building Coalitions

Why Build a Coalition?

Policy makers are much more likely to respond to advocacy efforts if a coalition representing key stakeholders is working together to deliver a shared message. For example, a minister of health or finance may easily dismiss an NTD funding request when it is only being made by the NTD programs. However, it is much more difficult to dismiss the same request when community organizations, religious leaders, and other government officials are also making it.

It is important to include credible and well-respected groups in such a coalition, including

- NTD program managers in the MOH
- WHO in-country office representatives
- NGOs involved in NTD work
- NGOs involved in other health work targeting shared vulnerable populations
- International partners, including donor pharmaceutical companies
- Recognized NTD experts
- Voluntary organizations, including the Lions Clubs or Rotary International
- Other important stakeholders in your country

The budgets of government agencies rarely change unless external political conditions require them to do so. Health budgets and development assistance budgets are no exceptions. Until an array of partners demands increased action and funding, NTDs may not be considered a high priority for your government.

Exercise 5

Make a list of individuals and organizations who you think should be a part of your advocacy coalition. Be sure to include all groups that have an interest in supporting NTD programs. Also, be sure to identify groups that are particularly effective at influencing decision makers.

Please complete worksheet on pages 42-43.

How to Attract New Partners to Join Your Coalition

Often, your advocacy coalition will be made up of organizations and individuals with whom you already work. However, you may identify additional potential partners who would be particularly helpful as you carry out your advocacy activities. When choosing partners to include in your advocacy coalition, be sure to include organizations and individuals that would be helpful to achieving your identified advocacy objectives. Remember, this is not just a broad support group but an action-oriented organization with clear activities to support your goals and objectives.

The following are some tips for involving a new partner in your coalition:

1) **Prioritize your target list.** What organizations and individuals will be most helpful for your advocacy activities? To whom do you have the best access? Who is most likely to support your cause given their involvement in other issues?
2) **Research your top targets.** What role have they played on other issues? Who influences them? Do you have any mutual acquaintances?
3) **Determine what you want.** Prior to making contact with the potential partner, have a clear idea of how you would like them to be involved. However, be prepared to completely revise your request should they show interest in collaborating in another area.
4) **Develop your presentation.** Gather the relevant facts and information to make your case. Determine the most persuasive way to present this information. *(See the tools in Section 3 to assist you in developing your presentation)*
5) **Make contact.** Introduce yourself and your organization by phone or letter, or preferably both. The primary objective of this initial contact should be only to arrange a personal meeting, not to gain support at this stage.
6) **Make your visit.** Be clear about the purpose of your visit and what you are asking the potential partner to do. Listen carefully to the potential partner's interests and explore those issues that seem to interest and excite them. Ask for his or her support in a specific area. At the end of the meeting, identify the next steps you will take to follow up on any concerns, ideas, or areas of interest.
7) **Make follow-up visits.** Find legitimate ways to follow up on your original conversation and keep your partner informed about exciting developments in the NTD community. Start to build a relationship.
8) **Use other ways to reinforce your visit.** Find other opportunities to ensure your potential partner is being asked to consider the NTD burden. For example, letters from other organizations or questions from journalists might encourage them to take a stand on the issue.
9) **Identify a "first step" activity.** In most cases, your first request should be an activity that is easy for the new partner to undertake.
10) **Be generous in your thanks** and ask for further involvement.

Benefits and Limitations of Coalitions

As you are likely aware, there are both positive and negative aspects to carrying out your advocacy efforts while working in a coalition. These pros and cons should be weighed when deciding what groups to involve and which are better to leave out of your coalition (see **Table 2**).

Table 2: Benefits and Limitations of Coalitions

Benefits	Limitations
Advocating with multiple partners leads to a stronger, more credible argument.	If the coalition is too broad, there is a risk of losing focus on what you initially set out to achieve as other interests are introduced and compromises become necessary.
Policy makers are more likely to listen when multiple voices are pushing for the same policy change.	Credit for successes and achievements is shared among all members, even if certain organizations were more involved than others.
Coalition members will have different strengths that they can contribute to the advocacy efforts.	Groups representing varying interests may not always get along. The inability to work out disagreements can harm the coalition's achievement of its goals.
Working together with multiple organizations increases the financial support available to carry out advocacy activities.	Smaller organizations may not have the same amount of influence in the group's decision making as larger organizations.
Coalition members will bring new contacts and connections that your organization may not have.	Organizing and managing a coalition can be more time consuming and complicated than carrying out activities on your own.

4. Involving Advocacy "Champions"

Identifying Champions

While coalitions can be very effective, it is extremely important to have one or more advocacy "champions." An advocacy champion can fulfill one of the following two roles:

- **Point person:** to coordinate advocacy activities and ensure that efforts move forward according to the advocacy plan and timeline.

  You will want this person not only to have the traits identified below, but also to have strong organizational skills, a persistent personality, and either good relationships with or a position within a key government office.

- **Spokesperson(s):** to publicize efforts to garner local and national attention for NTDs and integrated control efforts.

  In spokespersons, you are looking for people (the more the better!) whose influence, celebrity, or position can attract the attention of the public or of key decision makers.

For either of these "champion" roles, the following traits are essential:

- Excellent communication skills
- Knowledge of the importance of integrated NTD control efforts
- Sustained commitment to the issue
- Personal and passionate dedication to advocating for a sustained control effort to improve health and reduce poverty

5. Developing Messages to Support Country-Specific Goals

Developing Effective Messages

When developing advocacy messages, focus on expressing what your organization wants to achieve, why it is important, how you will be able to achieve it, and what the audience can do to help you achieve your goal.

There are five aspects to developing effective messages.

1. Content

One of the most important things to keep in mind when developing key messages for your advocacy activities is to keep your message **simple**. Since your target audience is not often made up of scientists or physicians, providing details on the reasons for selecting a cut-off point of less than 1% microfilaremia for determining the endpoint of LF MDA is likely to lose the attention of your audience!

Focus on giving the problem a **human face**. Share pictures and stories of local NTD patients. This kind of message can be much more impactful than general statistics on disease prevalence.

Express the **urgency** of treating the NTDs now, particularly given the unprecedented global commitment to NTDs during the past few years. Convey the importance of continuing and scaling up treatments so that all the hard work accomplished by national and international partners is not wasted.

You will also want to **tailor** the type of message you are sending based on the audience you are trying to reach. For example, the content and wording of your message may be different in a letter to a policy maker than on a radio spot.

2. Language

Consider whether there are certain words that you should or should not use. For example, rather than saying "There are five **endemic NTDs** in Burkina Faso" you may want to say "There are five **Neglected Tropical Diseases found in** Burkina Faso." Similarly, you may consider using

more familiar terms for disease names (i.e., instead of using "onchocerciasis" or "lymphatic filariasis," you may want to say "river blindness" and "elephantiasis," or use local terms for the diseases).

3. Source

The person or organization chosen to deliver the message is as important as how the message is delivered. Be sure to choose **credible** sources. The person chosen to deliver the message should be someone who is comfortable with addressing the target audience and with the method of communication. For example, some people are more comfortable with one-on-one meetings with high-level officials, but may not be comfortable with delivering a speech to the legislative body. Similarly, involving a celebrity sponsor in developing a radio spot may be more appropriate than having him or her meet with the minister of health.

4. Format

You should consider multiple methods of message delivery. Do not rely solely on radio ads and expect this to influence policy makers. Your advocacy plan should incorporate a whole range of activities including face-to-face meetings with influential people, letters to policy makers, brochures, news articles, press releases, and any other methods that are particularly useful in your country for getting your point across.

5. Time and Place

Consider whether there are particularly useful times and locations for getting your message out. Can you time the delivery of your message with a significant upcoming event? For example, news organizations are more likely to be interested in writing stories or running press releases about NTDs when there is an upcoming MDA. Additionally, your organization may consider inviting policy makers to the field to attend an MDA in a nearby village or visit a morbidity management training where patients will be in attendance.

Exercise 6

Develop a set of general communication messages by answering the following questions in 1–2 sentences each:

1) What is the problem?
2) What is the solution?
3) What will be the outcome if successful?
4) What is the cost?
5) What do you need to be successful?

Please complete worksheet on page 44.

Developing Messages to Reach Decision Makers and Influential People

Make it clear why they should support integrated NTD programs. In resource-constrained economies, you will have to persuade decision makers and other influential people why they should be providing support for NTDs. Emphasize the enormous benefit achieved through NTD interventions with minimal cost. Highlight the commitment of the global community to eliminating or controlling these diseases. Point out the generous donations by pharmaceutical companies that make success possible.

Explain what you need them to do to help. Be sure you have a clear explanation of the types of support you need from this audience, and why this support is necessary to achieve your goal.

Some suggested message formats for reaching this audience include

- Face-to-face meetings
- Letters
- Field visits to meet patients and/or participate in MDA
- Fact sheets
- Brochures
- Presentations
- Newspaper articles
- Television coverage
- Special events

Developing Messages to Reach the General Public

The general public is an important constituency that can help persuade policy makers about the importance of supporting NTD programs. While this is not the primary audience of your advocacy efforts, the general public is an important component to include in a well-rounded advocacy plan.

Messages to the general public should be even simpler and more concise than messages to policy makers, and should focus on how NTD programs are benefitting their families and communities.

Some suggested message formats for reaching this audience include

- Presentations at community meetings
- Billboards
- Pamphlets and fliers
- Radio shows
- Newspaper articles or advertisements

Tips for Building Support from Policy Makers

- Examine the policy maker's history of involvement in NTDs and other health issues. Note which individuals and institutions seem to have influence on the policy maker, and determine what type of initiatives the policy maker has previously supported. For example, many senior MOH officials will have personal experience with these NTDs, either with an infection themselves or within their family. This is a good way to personalize the issues.
- Use a number of different communications channels to reach an important policy maker. Points of entry include "insiders," such as the policy maker's staff, friends, and associates, and "outsiders," such as the media and influential organizations. Your advocacy coalition members may have different contacts that will be helpful in providing various points of entry to reach the policy maker.
- Make sure the social and political relevance of your message is clear. Demonstrate that there is public concern about the control of NTDs in your country.
- Clearly articulate the threat of NTDs and the effectiveness of the global partnership targeting NTD control.
- Subtly suggest the potential political benefits of showing leadership on NTD control and the potential political consequences of failing to take action.
- Be aware of conflicting special interests that may have an influence on the policy maker's reaction to the issue.
- Once communication channels are opened, remain proactive. Maintain regular contact with the policy maker.

6. Evaluating Advocacy Efforts

Purpose of Evaluation

A key step that is often overlooked when undertaking advocacy activities is **evaluation** of your efforts. The importance of advocacy evaluation is to ensure that you are meeting the advocacy objectives you set at the beginning of the process. Determining whether the activities you have carried out have been successful or not will guide your planning for future activities and will improve your chances for greater success.

Documenting Advocacy Activities

As a first step, it is important to evaluate the advocacy activities that have been carried out. While it is very easy to tally the number of phone calls to policy makers, the number of meetings with government officials, and the number of news stories about NTDs, for example, these types of numbers do not always accurately portray the extent of your efforts.

In addition to raw numbers, we recommend that a journal of achievements be kept by the advocacy point person or "champion" with the following type of information included:

- Brief description of achievement
- List of activities that you believe led to the achievement *(meetings, telephone calls, news stories, etc.)*
- Other important points *(notable statements made by the person with whom you were speaking, exciting moments, etc.)*
- Lessons learned *(what worked, what did not, what you would do differently in the future)*
- Planned follow up/next steps

This journal of achievements should be discussed and reviewed on a semiannual basis with the RTI International grantee NTD coordinator so that: 1) adjustments can be made in the advocacy plan, if needed; and 2) the grantee can provide an annual report and regular updates on the status of in-country advocacy efforts to the RTI International NTD Control Program, who in turn can keep U.S. Government (USG) partners informed.

Operationalizing Objectives for Assessment

In addition to evaluating your advocacy activities, it is also important to measure the **outcomes** of your efforts based on the initial objectives created (see **Table 3**).

Table 3: Evaluating Your Advocacy Activities

Advocacy Goal	Advocacy Objectives	Intermediate Measures	Long-Term Outcomes
Control or eliminate NTDs through integrated implementation of MDA	Achieve the creation of a government budget line for NTD integration financing within the next 12 months	Number of government budget line(s) for NTDs compared to baseline; date of achievement	Sustainable financing of NTD programs Increased coverage and compliance and expanded program reach Government commitment towards long-term NTD control Integration of control programs into primary health care system Etc.
	In the next 2 years, increase government funding for NTD programs by 75%	Amount of government funding toward NTDs compared to baseline; date of achievement, etc.	

Worksheets to plan advocacy activities and assess progress are included on pages 52–53.

III. Tools and Resources: Handouts and Guides to Support Implementation

1. About the NTDs

1) Disease-specific information
2) Important endorsements of NTD integration
3) USAID support for NTD integration
4) Global PowerPoint presentation

2. About Advocacy

Setting Objectives

1) Checklist for analyzing an advocacy objective

3. Identifying Target Audiences

1) Policy Mapping: Audience Identification
2) Policy Mapping: Decision Making Process

4. Building Coalitions

1) Identifying Allies and Opponents

5. Communicating Effectively

1) Developing Messages by Target Audience *(Tip: Complete a new table for each target audience)*
2) Tips for Writing a Success Story
3) Tips for Writing Letters to Government Officials
4) Tips for Effective Presentations
5) Tips for Developing Effective Print Materials
6) Tips for preparing an Effective News Release
7) Tips for Planning a News Conference

6. Creating an Advocacy Plan

1) Advocacy Plan Worksheet

7. Evaluating Advocacy Efforts

1) Advocacy Assessment Worksheet

Lymphatic Filariasis

Summary Statement

More commonly known as "elephantiasis," lymphatic filariasis (LF) is a parasitic infection that threatens severe and disfiguring disability to the more than 1.3 billion people at risk in more than 80 countries worldwide.

Disease Burden

- 1.3 billion people at risk of infection[1]
- 120 million people already infected[2]
- Endemic in 81 countries in Southeast Asia, Africa, the Pacific, and the Americas[1]

Morbidity

- Filarial worms cause damage to the lymphatic vessels that result in lymph fluid accumulation, particularly in the limbs and genitals.
- *Lymphedema*—painful and disabling swelling, typically in the lower limbs.
- *Elephantiasis*—a severe stage of lymphedema in which the skin of the swollen limb becomes hard and thick due to repeated bacterial and/or fungal infections.
- *Hydrocele*—swelling of the scrotal sac.
- An estimated 15 million people are currently suffering from lymphedema or elephantiasis and 25 million are suffering from hydrocele caused by LF.

Disease Cycle

- LF is caused by a parasitic worm.
- Infective parasitic larvae are deposited by an infected mosquito on the skin of a human during a blood meal; the larvae enter the bite to infect the human.
- The larvae grow and reproduce in the human's lymphatic system and release microscopic worms (called microfilariae) into the infected human's bloodstream.
- When a mosquito bites the infected human, it sucks up the microfilariae, which then develop into infective larvae again inside the mosquito.
- The infective larvae are transmitted to the next human during a mosquito bite, and the cycle of infection continues.

1 WHO. 2008. Global Programme to Eliminate Lymphatic Filariasis. *Weekly Epidemiological Record* 83: 333–348.
2 Ottesen EA. 2006. Lymphatic filariasis: Treatment, control and elimination. *Advances in Parasitology* 61: 395–441.

Strategies to address LF

- In 1997, the World Health Assembly passed a resolution calling for the elimination of LF as a public health problem.
- The strategy focuses on eliminating transmission of the disease by administering WHO-approved drug regimens for five years to all at-risk populations.
- For patients already suffering from LF morbidity, the recommended strategy is hygiene management. Patients are taught to keep the affected areas clean, to avoid bacterial or fungal infections, which worsen the manifestation.

Drug Donations

- In 1997, **GlaxoSmithKline** committed to donating as much albendazole as necessary for as long as necessary to eliminate LF. Albendazole is co-administered with diethylcarbamazine or Mectizan®.
- In 1998, **Merck & Co., Inc.** committed to donating Mectizan® to be co-administered with albendazole in Africa and Yemen, where onchocerciasis is co-endemic.

Onchocerciasis

Summary Statement

More than 100 million people are at risk of blindness and disfiguring skin disease resulting from the parasitic infection onchocerciasis also known as "river blindness."

Disease Burden

- More than 100 million people at risk of infection[1]
- 18 million people already infected[2]
- Endemic in 35 countries in Africa, the Middle East, and Latin America[3]

Morbidity

- Dying microfilariae create an inflammatory response in the skin and eyes, leading to disfiguring skin disease and disabling impaired vision.
- *Eye manifestations*—Onchocerciasis is the second leading cause of blindness of infectious origin. Over time, inflammatory responses to microfilariae lead to sensitivity to light, diminished vision, and eventually blindness.
- *Skin disease*—Infected patients develop severe dermatitis, which causes intense itching. The skin becomes swollen, thickened, and eventually loses pigment, a disfiguring condition called "lizard skin."
- 800,000 patients are already visually impaired and another 270,000 are blind.

Disease Cycle

- Onchocerciasis is a parasitic infection spread by black flies.
- Infective larvae are transmitted to humans when the infected black fly takes its blood meal.
- In the human, the parasites form nodules in the tissues. The parasite grows and reproduces, releasing millions of microfilariae into tissues.
- Subsequent black fly bites of infected humans continue the cycle of transmission between flies and humans.

1 WHO. 2000. Fact sheet #95. Onchocerciasis (River Blindness).
2 Richards FO, Boatin B, Sauerbrey M, Seketeli A. 2001. Control of onchocerciasis today: Status and challenges. *Trends in Parasitology*. 17(12):558–563.
3 WHO Expert Committee on Onchocerciasis. Third report—Technical Series 752. WHO, Geneva 1987.

Strategies to Address Onchocerciasis

- In Africa, onchocerciasis programs aim to control the disease; in Yemen and Latin America the strategy is elimination of transmission.
- The treatment strategy focuses on twice-yearly mass treatment with Mectizan® in endemic areas.
- Treatment with Mectizan® reduces transmission and alleviates suffering in those already infected.

Drug Donations

- In 1987, **Merck & Co., Inc.** committed to donating as much Mectizan® as necessary for as long as needed.

Soil-Transmitted Helminths

Summary Statement

Soil transmitted helminths (STH), more commonly known as "intestinal parasites," are common throughout the world and result in poor cognitive and physical development.

Disease Burden

- Over 4 billion people at risk[1]
- 1.2 billion people already infected[1]
- Endemic in 130 countries around the world[2]

Morbidity

- STH cause stunted growth, anemia, and decreased cognitive and physical development.

Disease Cycle

- STH are three types of worms—1) *Ascaris lumbricoides* (roundworms), 2) *Trichuris trichiura* (whipworms), and 3) hookworms—that are spread when humans ingest the eggs or larvae penetrate the skin.
- People with intestinal parasite infections eliminate worm eggs in their feces.
- In areas with poor sanitation, the soil and water becomes contaminated with worm eggs that are then spread to other community members.

Strategies to Address STH

- In 2001, the World Health Assembly passed a resolution calling for at least 75% of at-risk school-age children to be treated regularly for schistosomiasis and intestinal parasites by 2010.
- STH are addressed through improvements in water and sanitation, hygiene education, and twice-annual treatment with an anthelmintic drug, typically mebendazole or albendazole.

Drug Donations

- **Johnson & Johnson** is committed to donating mebendazole to treat up to 25 million children (50 million doses) per year for STH.

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1 de Silva NR, Brooker S, Hotez PJ, Montresor A, Engels D, Savioli L. 2003. Soil-transmitted helminth infections: Updating the global picture. *Trends in Parasitology*. 19(12):547–551.

2 WHO. 2008. Soil-Transmitted Helminthiasis – Progress report on number of children treated with anthelminthic drugs: an update towards the 2010 global target. *Weekly Epidemiological Record* 83: 237–252.

Schistosomiasis

Summary Statement

Schistosomiasis sometimes called "snail fever" is a parasitic worm infection threatening 650 million people worldwide with stunted growth cognitive impairment severe damage to organs and death.

Disease Burden

- 650 million people at risk[1]
- 200 million people already infected[2]
- 74 endemic countries in Africa, the Americas, Southeast Asia, and the Middle East[3]

Morbidity

- Morbidity related to schistosomiasis is caused by an immune reaction to the eggs released into body tissues.
- *Urinary schistosomiasis*—results in damage to the bladder, ureters, and kidneys over time.
- *Intestinal schistosomiasis*—results in damage to the intestines, enlargement of the liver and spleen, and hypertension in abdominal blood vessels.
- 112 million people suffer from urinary schistosomiasis; 54 million people suffer from intestinal schistosomiasis.

Disease Cycle

- Schistosomiasis is a parasitic infection cause by flatworms called *Schistosoma*.
- Infective larvae are released by freshwater snails into bodies of water. As humans enter the water to bathe and do laundry, the larvae penetrate their skin.
- Once in the body, the worms grow and develop in the blood vessels. Eggs are passed through urine and feces into water sources, where the larvae that are released again infect freshwater snails.

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1 Engels D, et al. 2002. The global epidemiological situation of schistosomiasis and new approaches to control and research. *Acta Tropica*. 82:139–146.

2 WHO TDR. 2004. Schistosomiasis. TDR/Nature Reviews Microbiology Disease Watch.

3 Chitsulo L., Engels D., Montresor A., Savioli L. 2000. The global status of schistosomiasis and its control. *Acta Tropica,* 77: 41–51.

Strategies to Address Schistosomiasis

- In 2001, the World Health Assembly passed a resolution calling for at least 75% of at-risk school-age children to be treated regularly for schistosomiasis and intestinal parasites by 2010.
- The WHO-approved strategy focuses on targeted treatments with praziquantel of at-risk school-age children.
- According to WHO, effective schistosomiasis control is based on regular drug treatment, snail control, improved sanitation, and health education.

Drug Donations

- In 2007, **Merck KGaA** committed to donating 200 million tablets of praziquantel through 2017 to countries with high schistosomiasis disease burden.

Trachoma

Summary Statement

As the leading cause of preventable blindness worldwide, trachoma can be eliminated by addressing active infections with antibiotics and surgery and preventing future infections by teaching hygiene and improving access to clean water and improved sanitation.

Disease Burden

- Over 40 million people suffer from active infection[1]
- Endemic in 56 countries in Africa, Asia, the Americas, the Pacific, and the Middle East[1]

Morbidity

- Repeated infections scar the eyelids, which cause eyelashes to turn inward and scratch the cornea. Over time, this painful condition leads to blindness.
- *Trachomatis trichiasis*—This advanced stage of trachoma infection is characterized by extensive scarring inside the eyelids and inward-turned eyelashes. It can be addressed through surgical intervention.
- 8 million patients are already blind as a result of trachoma. An additional 41 million have active infection.

Disease Cycle

- Trachoma is caused by the bacterial infection *Chlamydia trachomatis*.
- This highly infectious bacterium is easily spread through person-to-person contact and by flies that come into contact with the eyes or nose of an infected person.

Strategies to Address Trachoma

- In 1998, the World Health Assembly passed a resolution calling for the global elimination of trachoma by 2020.
- Trachoma elimination centers on the four-step "SAFE" strategy: **S**urgery to correct advanced stages of disease; **A**ntibiotics given once-yearly for 3 years to at-risk populations; **F**ace washing to reduce the spread of infection; and **E**nvironmental change to increase access to clean water and improved sanitation.

Drug Donations

- In 1998, Pfizer committed to donating the antibiotic Zithromax® toward the elimination of blinding trachoma.

[1] International Trachoma Initiative Web site. www.trachoma.org.

Important Endorsements of NTD Integration

"It quickly became clear that this story is not just about the staggering numbers of the world's citizens overwhelmed by HIV, AIDS, TB, and malaria. And it's not just the story about one billion people who are afflicted with disabling, oftentimes stigmatizing, neglected tropical diseases, such as human hookworm infection and elephantiasis... it's all about the faces of dying children and sick mothers who haunt those who have seen them...What struck me, and what I think struck us all...that these challenges are all interconnected."

Bill Clinton
Former President of the United States

While visiting Ghana on a multi-country trip to Africa, former U.S. President George W. Bush asked the world to reduce dramatically, and eventually control and eliminate, the burden of NTDs as a major threat to health and economic growth in the developing world.

"We will fight neglected tropical disease. And we won't confront illnesses in isolation—we will invest in public health systems that promote wellness and focus on the health of mothers and children."

U.S. President Barack Obama in a speech before
the Ghanaian Parliament
July 2009

"These diseases [NTDs] are also a burden for health systems. For many other infectious diseases, management is an intermittent emergency. The patient either survives or dies. This is not the case for these diseases, where the misery is prolonged."

Margaret Chan,
Director General, WHO

"Comprehensive, Africa-wide control of malaria and NTDs together would probably cost no more than $3 billion per year, or just two days of Pentagon spending. If each of the billion people in the rich world devoted the equivalent of one $3 coffee per year to the cause, several million children every year would be spared of death and debility, and the world would be spared the grave risks when disease and despair run unchecked."

Jeffrey Sachs,
Director of the Earth Institute

Talking Points on the USAID Initiative: Why Endemic Country Government Commitment to Additional Funding is Necessary

Principle of additionality: The NTD Control Program aims to supplement existing government resources and donor support with the goal of increasing MDA coverage and expanding to additional at-risk populations.

MDA-focused funding: The focus of the NTD Control Program funding is on MDA; additional program funds are necessary for

- Monitoring and evaluation
- Morbidity management, including hydrocele surgery and limb washing for LF and trichiasis surgeries for trachoma
- Water and sanitation (for trachoma, soil-transmitted helminths)

Time-limited commitment: The current USG commitment provides funding for integrated MDA for NTDs through 2013. Reaching program sustainability is critical to ensure the continuation of control programs targeting schistosomiasis, STH, and onchocerciasis, even after the elimination of the other diseases (see **Figure 5**).

Figure 5: Expanded Continuum of Sustainability

	Stage 1	Stage 2	Stage 3	Stage 4
Program Benchmarks	• Existing stand-alone NTD programs, or some knowledge of disease endemicity, but no integrated national strategy or plan of action	• National integrated NTD Plan of Action, preferably developed with WHO, approved by government • National Task Force for integrated NTD control established • Government established budget allocation for NTDs	• Government-led advocacy efforts established among country stakeholders, regionally, and globally • NTD control integrated with other health programs (e.g., malaria, school health) • Multiple ministries involved in NTD control (e.g., planning, finance, health, education, environment, etc.)	• Government allocating basket funds for NTD control • Post-elimination strategies finalized and ready to implement • Control diseases (e.g., schistosomiasis and STH) fully integrated into other health programs • Funding leveraged for clean water, sanitation, IVM, and morbidity
Program Activities	• Conduct mapping to determine problem and disease overlap • Identify stakeholders • Establish relationships with regional NTD programs, drug donation programs, and technical assistance partners • Develop National Plan of Action and budget projections	• Initiate MDA and other NTD control activities • Establish M&E reporting systems to monitor program • Scale up programs nationally and incorporate all diseases • Investigate other programs for integration (e.g., malaria, child health)	• Continue MDA, expand morbidity control • Develop post-elimination strategies and plans • Refine disease maps to identify areas of remaining disease, possible recrudescence, intensified treatment strategies to achieve elimination	• Annual MDA as required for disease control
Advocacy Interventions	• Advocate for National Plan of Action • Advocate for funding from range of donors	• Community mobilization • Coalition building • Identify champions in government and society • Provide regular data and program achievements to donors and stakeholders	• Document successes to sustain and increase government ownership and commitment • Work with government to leverage best practices and successes for other health programs • Expand focus beyond health sector to include environment and education sectors	• Assure inclusion of NTD control strategies in national health policies even after elimination to avoid resurgence

Unsustainable ⟷ **Sustainable**

Checklist for Analyzing an Advocacy Objective

ADVOCACY OBJECTIVE:	
IMPORTANT CONSIDERATIONS	**YOUR THOUGHTS**
Is the objective clear and concise? Can you easily explain it to all stakeholders?	
What is the timeframe of your objective? Can the objective realistically be achieved during that timeframe?	
Who are the key decision makers who need to be targeted to achieve this objective? What are their positions? Do you have contacts who can help you reach these target decision makers?	
What organizations or individuals do you need to include in a coalition to help you reach this objective?	

Policy Mapping: Decision-Making Process

ORGANIZATION:	
What is the formal decision-making process?	
Where are there potential access points into the process? How can this process be influenced informally?	
Who are the key decision makers?	
What is the timeline for the decision-making process?	
How can we influence the process? What types of activities would be useful?	

Policy Mapping: Audience Identification

ADVOCACY OBJECTIVE:	
PRIMARY AUDIENCE TARGETS	**SECONDARY AUDIENCE/INFLUENTIALS**
Example: Minister of Education	***Teachers union*** ***Newspapers*** ***UNICEF*** ***Minister of Finance***

Identifying Allies and Opponents

ALLIES	
Who already supports NTD efforts in your country?	
In addition to the organizations listed above, who will benefit from your successful advocacy efforts?	
Are there particular government institutions that will benefit from your successful advocacy efforts? How?	
Are there individuals, for example government officials, who would benefit from your efforts? How?	
What companies in the private sector would be appropriate allies for NTDs in your country?	
Are there any other organizations that you think may be helpful in achieving your advocacy goal?	

OPPONENTS	
Are there any organizations that would be opposed to NTD advocacy efforts?	
Are there specific groups that would lose if your advocacy goals are successful?	
Are there government institutions that would oppose your advocacy goals?	
Are there any individuals, for example government officials, that would be harmed by your NTD advocacy efforts? How?	
Could there be any other groups that may be opposed to your advocacy goals?	

Developing Messages by Target Audience

AUDIENCE:	
Desired outcome	
Key message	
Most effective format(s)	
Who should deliver the message?	
When the message should be delivered?	
Where the message should be delivered?	

Tips for Writing a Success Story

Audiences

- Citizens of the U.S. and the U.S. Congress
- Citizens of your country
- The government of your country
- The media and Internet
- Donors
- Board members for your organization
- Potential donors

Elements

- A good story has a beginning that hooks the reader, a middle that explains the main issue, and an end that makes the story memorable
- Keep it short (one-page maximum), simple and straightforward
- Include a quote
- Insert a photo that illustrates your story and include a caption
- Mention your donor(s)
- Use simple language: Avoid jargon and always define acronyms and abbreviations
- Avoid too many statistics
- Human interest: Include information about how your program has impacted people and communities

Success Story Uses

- Share with country partners
- Attach them to your donor or internal reports
- Give them to visitors
- Put them on the Web site/ post them walls
- Give them to journalists

Success Story Evaluation

- Does it generate interest?
- Does it maintain interest?
- Is it highlighting one main issue, i.e., not overloaded?
- Does it have a personal touch, i.e., a human face?
- Is it short, simple, and straight forward?
- Is it well-structured?
- Is it interesting, and does it make you want to learn more?
- Is it addressing the target audience?
- Are the statistics minimal and reader-friendly?
- Do you have a signed photo consent form (if child, parental consent form) to use the photo?

Tips for Writing Letters to Government Officials

- Keep the messages **clear**, **concise**, and **simple**. Maintain focus on a select few issues.
- Support your points with **data**, **statistics**, and **human interest** stories.
- Make sure to **clearly state what you are asking the government official to do**. For example, do you want to schedule a meeting? Are you requesting funding? Do you want the government official to visit an NTD site?
- Maintain an **upbeat** tone throughout your letter. Mention all of the positive aspects of NTD control, including the enormous global partnership and commitment to the disease programs.
- Be **respectful** and use formal language.
- Be clear how you will **follow up**. Specify when you will contact him/her again. Be sure to actually follow up as you say you will.
- Ask other **partner organizations** in your coalition to also send letters to the same officials. Hearing the same key points multiple times from different parties will reinforce your message.

Tips for Effective Presentations

- Review the physical set-up of the room before speaking. Note the room size, acoustics, microphone, and audio-visual set up.
- Focus your presentation on one or two main messages. Repeat these main messages in different ways, again and again.
- Do not turn your presentation into a recitation of facts and data. Your main message could be lost if you bombard your audience with too much information.
- The more comfortable you are with the presentation, the more dynamic you will be. Practice giving your presentation in front of a colleague who can offer comments on how to improve your delivery.
- Make a good first impression. Memorize the first part of your presentation. Be confident.
- Make eye contact with your audience. Change your pace, tone, and hand gestures at key points to make an impact.
- Use powerful visual aids to emphasize main points. One well-planned photograph or chart can be worth a thousand words.
- Make sure overheads or slides can be quickly understood. Avoid complex graphs, small type, and too many words. As a rule of thumb, print no more than 50 words on one slide. Be sure everything can be clearly read from the back of the room.
- Your enthusiasm and concern about the issue will often be remembered more than the words you say.
- Keep to your time limit and allow time for questions. This is a critical opportunity to keep your audience engaged and excited about the topic.

Tips for Developing Effective Print Materials

- Determine **who** you need to reach and **why**.
- Keep the message and the design **simple**. Do not lose sight of your main message by introducing too many different topics, and do not present the material in a cluttered manner.
- Make it **clear** how support from the individual or organization will benefit your goals.
- Ensure that the **audience feels connected** to the importance of NTD programs by highlighting the "human" aspect of the impact of NTDs.
- Do not rely on words only. Incorporate compelling **photographs**, an eye-catching **format**, or other ways to interest your audience in reading your publication.
- If you need to present technical or scientific data, present it in **easy-to-understand language**. Use only the data needed to support your message, and use graphs or other visual features to explain complex issues.
- Too much information can overload the reader. A lengthy publication is not usually as effective as a **concise**, targeted one.
- **Brand** your print materials with logos of partner organizations to demonstrate the vast network of support for NTD programs.

Tips for Preparing an Effective Press Release

Content

- The headline should be interesting and newsworthy. You want to catch someone's attention so that they will read the article.
- The first paragraph should contain the most important messages that you want people to know. Information should become more general as the article progresses.
- Insert quotes from relevant individuals to make the story more interesting and express opinions. Try to include a quote within the first three paragraphs of the story.
- Always include information on
  - What is happening?
  - When is it happening?
  - Where is it happening?
  - Who is telling you about it?
  - Why is this important?
- For additional background information, include briefing materials at the end to avoid making the press release too long.

Style

- Keep your sentences short (25–30 words maximum).
- Keep your paragraphs short (2–3 sentences maximum).
- Keep the overall press release short (1–2 pages maximum).
- Use simple words and sentence structures.
- Do not use terms that the general public will not understand.
- Do not make sentences overly descriptive by using many adjectives and adverbs.
- Be sure to proofread the press release carefully for any errors!

Layout

- Include the date at the top of the page. Specify if the press release is "Embargoed for release" on a specific date (to coincide with a special event or the release of a report) or if it is "For immediate release."
- At the bottom of the release, include contact names and telephone numbers for more information.

Tips for Planning a News Conference

Reasons for Holding a News Conference

- To inform the public of an important and newsworthy story
- For occasions when your group has the participation of high-profile speakers or celebrities
- To release important new findings or research data
- To launch a major new initiative
- To announce something of great importance to your local area or country

Location and Setup

- Choose a centrally located, well-known, and easily accessible location that is convenient for journalists.
- Avoid selecting a room that is too large for the anticipated crowd; this can give the appearance that the event was poorly attended.
- Identify space in the room for camera equipment, if possible on an elevated platform.
- Reserve an additional quiet room for radio interviews after the news conference.
- Just prior to the event, ensure that all lights and sound systems are working properly.
- Ensure that there is a podium and a table with adequate seating for all spokespeople at the front of the room.
- Consider hanging a large branded sign on the front of or behind the podium.
- Have a sign-in sheet for journalists so that afterwards you can remember who attended.
- Consider having light refreshments available for after the news conference.

Timing

- Ensure that you are not competing with other newsworthy events on the same day.
- Begin the event on time.

Press Kits

- A news release
- A list and short bios of all spokespeople at the news conference
- Contact information for follow-up questions
- Additional publications or other informational materials

Advocacy Plan Worksheet

Advocacy Objective:				
Activity	**Desired Outcome**	**Resources Needed**	**Responsible Persons**	**Timeline**

Advocacy Assessment Worksheet

Description of Achievement	List of Activities Leading to Achievement	Other Important Points	Lessons Learned	Next Steps