

The Eliminate Neglected Diseases (END) Act of 2005

Summary

Why?

Neglected diseases are diseases that don't get much attention: malaria, tuberculosis, acute respiratory infections, infectious diarrhea. Given the following, conditions have never been better for the U.S. to apply inexpensive, relatively simple interventions to save lives:

- We know how to cure and/or prevent these diseases.
- Interventions (prevention and/or treatment) are relatively cheap (Cure for malaria = \$2. For TB = \$11-15. One year of non-curative treatment for AIDS: \$500-1000).
- These diseases are responsible for the vast majority of deaths in the developing world, particularly among children and pregnant women. Malaria is the number one killer of kids and pregnant women in Africa, kills between 1-2M people each year but makes about 500M sick! Tuberculosis kills about 2M people each year. Unlike with other diseases, people can not avoid infection with these killers by behavior change.
- Low-hanging fruit - these diseases are so cheap to control, even the modest budgets we have now could make a huge difference if they were spent wisely.

What does the bill do?

The END Act of 2005 focuses on the following programmatic reforms:

- 1) **Direct interventions:** requires funding of activities that have a direct impact on sick people or people at risk of becoming sick. For some programs, this will require a shift of priority in budgets from indirect support and advice-giving consultants to actually funding medical treatment, commodity procurement, and disease control activities.
- 2) **Accountability:** programs must measure performance and prove that they are saving lives. The bill establishes mechanisms to revise or terminate contracts that fail to save lives.
- 3) **Transparency:** Every dollar that the agency awards to combat infectious diseases must be accounted for on a public web site, similar to the Global Fund's web site. All signed agreements are posted online, as well as progress reports documenting performance on required deliverables and indicators.
- 4) **Scientific and Clinical Integrity:** The bill provides that clinical/medical and public health programs are overseen by the agencies of the Federal government where the core competencies in clinical medicine and public health reside. For programs where the lack of clinical and scientific expertise has been particularly acute, a group of Federal and non-government medical and academic experts will provide scientific and medical oversight.
- 5) **Coordination and Priority-setting:** Up to five Federal agencies are currently involved in international malaria and tuberculosis programs. The bill would provide for clearer lines of authority and coordination for these programs, and require a strategic planning process to ensure that programs operate according to a outcome-focused 5-year plan.