# Communities Confront Confront HIV Stigma in Viet Nam



Participatory Interventions Reduce HIV-Related Stigma in Two Provinces











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# **Table of Contents**

Executive Summary	1
Intervention Summary	
Key Evaluation Findings	
Recommendations for Designing Programs to Reduce Stigma in Communities	2
Introduction	4
Description of the Community-Led Interventions	6
Intervention Principles	6
Community Activities	6
Evaluation of the Community-Led Stigma Reduction Interventions	9
Research Methods	9
Evaluation Results	12
Conclusions	25
Lessons Learned and Recommendations	27
Address All Three Immediately Actionable Drivers of Stigma	27
Program Implementation	28
Tackling HIV Stigma in Communities – It Can Be Done	30
References	31
Appendix A: Intervention Timeline	33
Appendix B: Descriptions of Key Community Intervention Activities and List of Tools	34
Appendix C: Fear and Value Driven Stigma: Items and Factor Analysis Results	37

# **Executive Summary**

### **Communities Confront HIV Stigma in Viet Nam**

Participatory Interventions Reduce HIV-Related Stigma in Two Provinces

eaders in Viet Nam and the broader global commu-**L**nity recognize that HIV stigma and discrimination is a crucial hurdle to curbing the AIDS pandemic. Stigma undermines countries' investments in HIV services and obstructs universal access to prevention, care and treatment. That said, HIV-related stigma is not inevitable or fixed. This report, Communities Confront HIV Stigma in Vietnam, adds to the growing body of evidence that community-based interventions can reduce HIV-related stigma—and in a relatively short time.

Since 2002, the Institute for Social Development Studies (ISDS) and the International Center for Research on Women (ICRW) have been working with the Communist Party of Viet Nam to fill knowledge gaps about stigma, build stigma-reduction capacity among community service providers and leaders, and provide concrete tools and recommendations to communities and their leaders for tackling stigma.

This report highlights the community interventions and results from the latest phase of the project (2005-2007), which involved work with community leaders and members in two provinces to increase their understanding of stigma and build capacity to reduce it. The interventions sought to address stigma's three immediately actionable drivers:1 (1) lack of awareness of stigma and its harmful effects; (2) fear of becoming infected with HIV through casual contact with people living with HIV (fear-driven stigma); and (3) value-driven stigma or the shame and blame associated with HIV and behavior considered to be immoral by social standards.

These efforts met with marked success. An evaluation of the interventions found that people's participation in the project activities led to a significant increase in their awareness of stigma and reductions in fear- and value-driven stigma as well as stigmatizing intentions and behavior. Still, levels of stigma remained high at the

1 ICRW's seminal study on stigma identified three common causes of stigma across contexts that can be addressed through interventions [1]. These are referred to as immediately actionable drivers of stigma. project's end, suggesting the need for continued efforts to sustain initial changes and further reduce stigma.

Despite the caveat, this phase of the broader project, "Reducing HIV and AIDS-Related Stigma and Discrimination in Viet Nam," demonstrates that it is possible to reduce stigma, and in doing so, begin to foster a more supportive environment for people affected by HIV. The interventions described in this report pave the way for further expansion of community-led stigma reduction in Viet Nam and elsewhere by providing a simple replicable model, practical stigma-reduction tools and key lessons learned.

### **Intervention Summary**

The community interventions highlighted in this report are part of ISDS' and ICRW's broader work with the Communist Party to reduce HIV stigma and discrimination in Viet Nam. The most recent phase focused on designing and implementing community interventions in two urban communities: Cam Dong and Cai Khe, located in Quang Ninh and Can Tho provinces, respectively.

Community activities included: (1) stigma-reduction sensitization workshops for authorities and representatives of social organizations; (2) a workshop for community members to develop their own stigma-reduction action plans; (3) communities implementing the action plans with technical support; and (4) monitoring and evaluating the program activities. The project evaluation used quantitative and qualitative methods, including a household survey administered to a random selection of households at baseline and endline to measure the effect of project activities. All activities used participatory methods, and community members led the design and implementation of the stigma-reduction activities that they devised in the community workshop.

### **Key Evaluation Findings**

### **Increased Awareness**

Awareness of HIV stigma increased among participants in both Cam Dong and Cai Khe. Participants' recognition of the Vietnamese word for stigma, ky thi, dramatically increased over the intervention period. The number of respondents who were able to give multiple correct examples of stigma also increased significantly. In addition, respondents increased their depth of understanding of the multiple forms of stigma. The qualitative data further substantiate these findings, showing that respondents' awareness increased from baseline to endline not only of what stigma is, but also that stigma should be reduced and why.

### **Reduced Fear-Driven Stigma**

Exposure to intervention activities was associated with significant reductions in fear-driven stigma. In both communities, peoples' fear of infection through casual contact reduced significantly after participating in intervention activities. For example, respondents at endline reported less fear of HIV infection by sharing an in-patient room, sharing a toilet, going to the dentist and having a manicure. Regression results indicate that the more activities a respondent reported being exposed to, the lower his or her score on the fear of casual contact index. Reductions in fear-driven stigma related to perceived potential for blood contact (e.g., manicures, haircuts, dentists) also were associated with program exposure, but in less magnitude and required exposure to a greater number of program activities.

The qualitative data also support these findings. At endline, respondents noted that they felt less fear in sitting and talking, shaking hands, sharing meals and dishes, and maintaining close relationships with people living with HIV. Respondents also were more confident after the intervention about how HIV was not transmitted, and this confidence translated into a greater degree of acceptance of people living with HIV and their family members. Some respondents, however, still feared coming in contact with blood in daily living situations.

### Reduced Value-Driven Stigma, though **Overall Levels Stayed High**

Reducing value-driven stigma requires a sustained program effort with sustained activities for community participants, particularly when initial levels are high. Exposure to intervention activities reduced value-driven stigma in both communities. Although statistically significant, the changes observed were small in magnitude and the overall level of value-driven stigma remained high. For example, respondents continued to express high levels of blame toward people living with HIV, injecting drug users and sex workers.

People need greater exposure to program interventions to significantly reduce value-related stigma compared to fear-related stigma or improving awareness of stigma. Both communities required exposure to three or more of the four activities assessed as part of the evaluation to see a statistically significant decrease at endline on the valuedriven stigma index.

### **Reduced Discrimination**

People's intent to discriminate based on HIV status decreased among survey respondents in both communities. When presented with three scenarios that involved interacting with a person living with HIV, the percentage of respondents reporting intent to engage in discriminatory behavior decreased significantly from baseline to endline. At endline, respondents who reported exposure to more project activities were less likely to report intent to engage in stigmatizing behavior.

The qualitative data confirm this finding through respondents' descriptions of their own actions and their observations of others' actions. The most common behavior changes cited were an increased willingness to: communicate freely with and sit close to people living with HIV; drink and eat in their homes; and attend funerals of and pay respects to people who died as a result of AIDS. Change also was evident in the testimonies of people living with HIV and their family members. Through in-depth interviews, people living with HIV confided that community members cared for and communicated with them more openly after the intervention. They also reported that these changes made them more confident and gave them a greater sense of self-worth.

### **Recommendations for Designing Programs to Reduce Stigma in Communities**

Interventions to reduce stigma in communities should address all three immediately actionable drivers of stigma: (1) lack of awareness of stigma and its harmful effects; (2) fear of becoming infected with HIV through casual contact with people with HIV; and (3) shame and blame associated with HIV and behavior considered to be immoral. For each of these, programs should focus on the following:

### • Build awareness of stigma:

- Create name recognition of the local word for
- Expand understanding of the specific forms of stigma in the community;

- Expand understanding of the harmful effects of stigma on individuals, families and the community;
- Create awareness about how stigma can influence the spread of HIV.

### • Reduce fear-driven stigma:

- Acknowledge that fear of a dangerous illness is natural;
- Discuss the root causes of these fears;
- Provide clear, specific and unambiguous information about the ways in which HIV can and cannot be transmitted;
- Provide specific information about what people can do to protect themselves from HIV infection, and practical steps to prevent transmission; and
- Give community members an opportunity to have their questions answered by informed and trusted individuals.

### Reduce value-driven stigma:

- Disassociate HIV infection from behaviors considered to be immoral;
- Address the stigma associated with disapproved behaviors linked to HIV, such as drug use and sex work:
- Help community members understand that choosing not to stigmatize people living with HIV is not the same as condoning unapproved behaviors; and
- In the Vietnamese context:
  - O De-link HIV from the concept of "social evils";2 and
  - O Develop tools/skills to address institutional stigma, such as that evident in the "social evils" campaigns instituted by the state.

Several broader lessons also emerged for program implementation:

- Build commitment to and ownership of the stigmareduction process among community leaders to obtain buy-in from the larger community. The involvement of trusted and respected opinion leaders, representing a range of groups in the community, was essential. These leaders helped raise awareness and reduce fear within the community, and were particularly influential for changing value-driven stigma.
- Build understanding and capacity for stigma reduction. To cultivate these community leaders as
- Viet Nam had waged a campaign against "social evils," which involved the "rehabilitation" of sex workers and drug users through confinement (sometimes enforced, sometimes voluntary). Although the government officially "de-linked" HIV and AIDS from the "social evils" campaign in 2000, the association remains in the minds of many people [2].

- champions for stigma reduction, it is important to build their knowledge of HIV and stigma; provide opportunities for them to address their own fears, misconceptions and attitudes; and build their capacity to reduce stigma.
- Address stigma through combined approaches. The evaluation data show that the more activities a respondent reported exposure to, the larger the increase in awareness of stigma and decrease in fear- and value-driven stigma, and greater decline in people's intent to engage in stigmatizing behavior. Multiple activities not only reinforce messages, but provide ongoing opportunities to engage on the issue, learn, and begin to change attitudes and behavior. Different activities reach and appeal to different segments of the community.
- Provide written materials with specific information of local relevance. It also helps to have respected community leaders review this information and provide feedback as well as have them distribute the materials and information within the broader community.

## Introduction

**T**IV stigma and discrimination has been recognized His singular and classification of the globally as a crucial challenge to controlling the AIDS pandemic. UNAIDS has identified stigma and discrimination as a key barrier to the scale up of universal access to prevention, care and treatment [3], while the 2006 U.N. General Assembly resolution notes that addressing stigma and discrimination is "...a critical element in combating the global HIV/AIDS pandemic." In Viet Nam, the government has placed high priority on fighting stigma and discrimination against people living with HIV, giving the issue prominence in its National Strategy for HIV and AIDS Prevention and Control to 2010 and Vision to 2020 and National AIDS Program [4], and highlighting the need to combat stigma and discrimination in HIV/AIDS prevention work in the 2006 National AIDS Law [5].

Stigma and discrimination undermines investments in the provision of all HIV services [6, 7]. Fear of being identified with HIV keeps people from learning and disclosing their HIV status, adopting preventive behavior, and accessing services and treatment [2, 8-17]. People living with HIV, as well as their families, often are subject to job loss, ostracism within their families and communities, separation from their children, and lack of care and support [1, 2, 18-25]. These effects are magnified for the very individuals and groups most at risk for HIV and therefore most in need of HIV services [26-32]. Without addressing stigma and discrimination, the effectiveness of all HIV programs will fall short of expectations.

While progress is being made in learning how to reduce stigma [6, 7, 33-36], particularly in the health care sector [37-42], major gaps remain in knowledge around how to intervene at the community level. Reducing stigma at the community level is essential to creating an enabling environment that allows individuals, particularly those most at risk of contracting HIV, to practice prevention and access care, treatment and support services. Unfortunately, many of these vulnerable individuals and populations already are experiencing stigma related to

drug use, sex work, gender and sexual identity, making it particularly challenging to reach them with HIV services [30, 43-45].

Since 2002, the Institute for Social Development Studies (ISDS) and the International Center for Research on Women (ICRW) have been working with the Communist Party of Viet Nam to address knowledge gaps about stigma, build stigma-reduction capacity, and provide concrete tools and recommendations for tackling stigma. The latest phase (2005-2007) consisted of: (1) sensitization and capacity-building activities at the provincial level, and (2) the implementation and evaluation of community-led stigma-reduction interventions in two communities. This report describes results from the second activity, focusing on the evaluation results in particular.

The community interventions took place in two urban communities highly affected by HIV: Cam Dong and Cai Khe, located in Quang Ninh and Can Tho provinces, respectively. The provinces and communities were selected in consultation with the Central Commission for Ideology and Culture (CCIC),3 the Provincial Department for Communication and Education (PDCE), and with representatives of relevant provincial agencies.

Cam Dong, with a population of 10,000, is one among 16 wards and communes of Cam Pha town, located in the northeast of Quang Ninh province in northern Viet Nam. Cai Khe, at the border of Can Tho city in southern Viet Nam, has a population of 24,000. At the start of the community stigma-reduction interventions, Cam Dong had been exposed to more HIV activities than Cai Khe, though neither had received stigma-reduction focused programs. Drug use is prevalent in Cam Dong, especially among young men, and both local party authorities and community members see it as a pressing problem.

<sup>3</sup> CCIC was later merged with another party department and the name changed to Commission for Education and Communication. However, during most of this intervention it was still CCIC, and is referred to as such in this document.

Many of the people living with HIV in Cam Dong also are known to be injecting drug users (IDUs). Drug use is an increasing issue in Cai Khe, but not as severe as in Cam Dong.

Community stigma-reduction intervention activities included: (1) stigma-reduction sensitization workshops for authorities and representatives of social organizations; (2) a workshop for communities to develop their own stigma-reduction action plans; (3) implementation of the action plans by the communities with technical support from the project; and (4) monitoring and evaluation of program activities. All activities used participatory methods, with community members leading their design and implementation in each community. Both quantitative and qualitative methods were used to assess the effectiveness of project activities.

# **Description of the Community-Led Interventions**

### **Intervention Principles**

The interventions incorporated the following general principles of stigma reduction that emerged from research findings in Viet Nam [2] and elsewhere [1, 11].

- (1) At a minimum, stigma-reduction activities must address the following three immediately actionable drivers of stigma:
- Lack of awareness and knowledge of stigma;
- Fear of acquiring HIV through everyday contact with infected people; and
- Values linking people with HIV to behavior considered improper and immoral.
- (2) Participatory methodologies should be used.
- (3) Intervention communities should develop capacity to reduce stigma and should feel ownership over the project.

### **Community Activities**

In the Vietnamese context, successful community-level interventions require building support at the central level down through the provincial to community governing structures. Through a partnership with the CCIC,4 a meeting with provincial party officials was held to discuss the possibility of working in their respective provinces. Once provincial authorities approved the project, a planning meeting with local community-level party officials was held to gain their buy-in and support for the intervention.

With all appropriate governing support in place, the project was launched in December 2005 with baseline data collection, followed by community intervention activities, which occurred in two phases. The first phase lasted six

months and consisted of working with community gatekeepers and opinion leaders to build their understanding of stigma and motivation to reduce it, design and plan the community-led activities, and determine how they would be implemented. Implementation of community intervention activities occurred in a second phase (14 months). Endline data collection occurred the month after the last intervention activity.5

The first step in the community intervention was a one-day HIV/AIDS knowledge-building and stigma sensitization workshop for community leaders from the people's committee, the party cell, heads of mass organizations (e.g., Women's and Youth Union, Fatherland Front), school principals and heads of residential clusters. There were 53 participants in Cai Khe and 46in Cam Dong. ISDS and CCIC staff facilitated with assistance from two local stigma-reduction trainers who had attended a provincial stigma-reduction training-oftrainers workshop.

The workshop began with a briefing on the HIV epidemic in Viet Nam and in the selected provinces and project sites, and then provided more detailed information (e.g., what is HIV and AIDS, modes of transmissions, myths of transmission through casual contact, prevention and care). Next the workshop addressed HIV-related stigma and discrimination: its manifestations, forms, root causes and consequences. This part addressed both fear-driven stigma (fear of acquiring HIV through everyday contact with infected people) and value-driven stigma (values linking people with HIV to behavior considered improper and immoral), the latter of which is especially associated with "social evils" in the Vietnamese context. The workshop concluded with a brainstorming session on activities to reduce stigma and discrimination in the community.

This partnership was developed in a previous phase of the project.

<sup>5</sup> Appendix A contains a detailed intervention implementation timeline.

Workshop methods included presentations and questions; illustrations (e.g., figures, charts, pictures); group work and participatory exercises from the toolkit, Understanding and Challenging HIV Stigma: Toolkit for Action6; and de-linking HIV and AIDS from "social evils."

A powerful component of the community sensitization workshops was the participation of people living with HIV as workshop participants, and if they felt comfortable, as resource people to share their experiences living with HIV. For many participants, it was the first time they had met a person living with HIV and heard about experiences of stigma and discrimination and efforts to live with dignity. Three local people living with HIV (two in Cam Dong, one in Cai Khe) chose to disclose their status at the workshop.

Next, an action-planning workshop was held in each community to design and plan activities to reduce stigma and discrimination. A subset of participants from the sensitization workshop participated, including the chairman and vice chairmen of the wards, key staff of the people's committee, the heads of residential clusters, school principals and the heads of mass organizations. One staff member of the provincial department of culture and education and one staff member of the district unit of culture and education also participated.

### **Action Planning Workshop Agenda:**

- Introduce designing an action plan
- Prioritize stigma-reduction activities proposed in community-sensitization workshop
- Group work on action plans
- Present action plans and feedback
- Prioritize activities and finalize a general community action plan
- Assign group implementation roles
- Work-planning/implementation schedule
- Establish project management unit

The action-planning workshop began with an introduction to the essential steps in developing an action plan, including budget estimation. A discussion followed of the stigma-reduction activities proposed during the sensitization workshop, including feasibility and most crucial activities. Participants then divided into small groups according to their particular task or work within the community structure. For instance, the leaders of the people's committee and the head of residential clusters formed

one group to discuss activities for community residents, while representatives of the women's union worked in a different group to discuss activities targeted to women. One member of the project team assisted each group. The groups presented their plan to the whole group for feedback. Next, participants combined all the individual action plans and prioritized activities according to the most relevant and feasible. The workshop concluded with a discussion about budget, schedules and monitoring.

A project management unit (PMU), consisting of a range of stakeholders from the community, such as representatives of mass and social organizations, as well as two representatives from the provincial level, was established at the end of the action planning workshop. One person in the PMU was assigned to be the local project coordinator. The PMU provided management oversight, monitored project implementation and provided activity updates through a formal quarterly reporting process to ISDS, and more informally and frequently via phone.

Due to the ambitious nature of the community action plans, a smaller meeting was held after the workshop with leaders of the people's committee and key representatives of both communes to make the plans more feasible, combine overlapping activities and get consensus on who was to do what pieces of the plan among the various stakeholders. Consensus was reached leading to a synthesized action plan for each community, with 12 activities in Cam Dong and 11 in Cai Khe (Table 1). Descriptions of the key community activities can be found in Appendix B. ISDS and representatives of the community people's committee of the project sites then signed a cooperative agreement to carry out the activities. The communities implemented the intervention activities over the next 14 months, with technical assistance from ISDS and CCIC.

Developed originally in Africa [46] the toolkit has been successfully adapted to and used in Viet Nam for the past five years [47].

### **Table 1: Community Action Plans**

No.	Cam Dong, Quang Ninh Province	Cai Khe, Can Tho Province		
	Sensitization of Comm	nunity Members		
1	Stigma-reduction training for community educators			
2	Sensitization meetings: community residents; women's union m	embers		
3	Household distribution of an HIV and stigma fact sheet			
	Communication	Activities		
4	Design and construct posters			
5	Develop, paint anti-stigma slogans on walls in the community	Broadcast anti-stigma themes on mobile vehicles and on local loudspeakers		
6	Develop anti-stigma scripts and perform them at a drama/play of	competition		
7	Poetry, story creation and performance by community elders and members of a support group of mothers and wives of drug users, and people living with HIV			
8	End-of-project community-wide event to showcase products (e.	g. drama) of community activities		
	School Acti	vities		
9	Anti-stigma school sensitization for teachers and students			
10	School drawing contest on anti-stigma theme			
	Assistance to People Living wit	h HIV and their Families		
11	Fact sheets and sensitization meetings on stigma reduction for a support group of mothers and wives of drug users, and people living with HIV	Assist formation of self-help group of people living with HIV and provide ongoing support		
	Integrate Anti-Stigma Criteria into Existing Party Campaign			
12	"No stigma toward people living with HIV and their families" added to criteria necessary to achieve title of "Culturally Well-Behaved Family"			

# **Evaluation of the Community-Led Stigma Reduction Interventions**

### **Research Methods**

### **Study Design**

The study used a pre- and post-intervention evaluation design. Both quantitative and qualitative methods were used before and after the intervention to assess changes in stigma at the community level and allow for triangulation of data. Specifically, the intervention sought to (1) increase awareness and understanding of stigma; (2) reduce fears of contracting HIV through casual contact; (3) reduce shame, blame and judgment attached to people living with HIV, including, in this context, the association of people living with HIV with the concept of "social evils"; and (4) reduce stigmatizing behaviors toward people living with HIV.

Ongoing process data were collected, including a midterm evaluation using qualitative interviews, to monitor progress of the project and provide ongoing feedback to the communities to improve implementation.

### Sampling

The study population included adult residents of the urban wards where the intervention was conducted. To be eligible for the study, participants had to be a resident in the ward for at least one year prior to the construction of the sampling frame and 18 years of age or older. A complete household listing was gathered for each ward, based on the residential cluster household registration logbook and with the assistance of appropriate local party officials. This household list served as the sampling frame for the baseline and endline surveys from which individual eligible residents were randomly selected at each data point.<sup>7</sup>

No prior data existed for the intervention populations about initial levels of different dimensions of stigma that the intervention was seeking to change (e.g., fear of casual contact, value-driven stigma). The sample size was calculated using a range of assumptions. These assumptions were based on previous qualitative data collection in Viet Nam, and survey data on stigma from other countries (e.g., Tanzania). Sample size was therefore calculated using the following: power 80 percent; confidence level 95 percent; ratio between group 1 (pre-intervention) and group 2 (post-intervention) = 1; and the most conservative numbers from the range of estimates for baseline stigma levels (60 percent level of value-based stigma, and an anticipated 10 percent drop post-intervention). A sample size of 700 for each site (both at baseline and endline) was determined to be adequate to assess whether the interventions had a significant effect on reducing stigma.

Purposive sampling was used to recruit participants from intervention communities for qualitative data collection at baseline, mid-term and endline. Specifically, anticipated beneficiaries of the project (e.g., community members, people living with HIV and their families, school children) were interviewed, as well as project implementers (e.g., program administrators, community educators, teachers). To access people living with HIV, staff of membership organizations or community-based organizations providing services to people living with HIV approached HIV-positive individuals with information about the project. If a person living with HIV expressed interest in participation, a study staff person asked permission to contact him or her with more information, and asked how and when was most convenient time to be contacted.

### **Ethical Procedures**

ISDS' scientific advisory committee reviewed and approved this study. All participants provided written informed consent prior to data collection. Study participants were given contact information of the principal investigator at ISDS whom they could contact directly

Cam Dong has a population of 10,000 people living in 2,500 households. The ward is divided into eight residential clusters. Cai Khe has a population of 24,000 living in 3,854 households. The ward is divided into eight residential clusters.

with questions or concerns regarding the study or their participation.

### **Quantitative Data**

Interviewers who were trained and supervised by ISDS collected survey data before and after the intervention activities. Table 2 presents the sample sizes for each province. In Cai Khe (CT), 1,399 residents were surveyed (695 at baseline; 704 at endline). Data were collected from 1,389 residents of Cam Dong (QN), 697 at baseline and 692 at endline. The surveys collected data on standard socio-demographic characteristics, knowledge of HIV transmission and prevention, proximity to (knowing) a person living with HIV, and exposure to media messages about HIV and stigma. In addition, the baseline and endline questionnaires contained items to measure awareness and understanding of stigma, fear of HIV transmission, and attitudes and behaviors toward HIV-positive individuals living in the community. Study participants were asked detailed questions about their exposure to intervention activities at endline. Quantitative measures for stigma and discrimination outcomes were developed and adapted from measures used in previous ICRW research projects, as well as recommendations from USAID's **Interagency Stigma and Discrimination Indicators** Working Group, of which ICRW was an active member [11, 48].

### **Qualitative Data**

Ninety seven in-depth interviews (IDIs) were conducted with 24 people living with HIV, 16 family members of people living with HIV and 57 community members residing in villages in the intervention wards. Community informants consisted of both regular community members (n=30) and community opinion leaders (n=25), including the chairman or vice chairman of the ward, stigma trainers from intervention communities, health workers, the program coordinator, ward leaders, representatives of mass organizations, school principals, chairpersons of clubs and self-help groups, provincial and

district members of the commission for education and culture, and people in charge of information and cultural activities at the ward level. All respondents were 18 years or older and were recruited using purposive sampling.

A total of 35 focus group discussions (FGDs) were conducted: 25 with a cross-section of community members, three with heads of residential cluster/units and seven with intervention target groups. Target groups included community educators, teachers, and primary and secondary school students.

Field workers trained in qualitative research methods conducted the IDIs and FGDs at baseline, mid-term and endline using semi-structured interview guides. Baseline and endline data were used to evaluate the effect of the program. Mid-term data were used to evaluate the process of intervention development and implementation and provide feedback to the communities on their progress. The interview guides covered a broad range of topics including understanding of stigma in the community, fear- and value-based stigma, enacted stigma (discrimination), and at endline, exposure to intervention activities and perceived change in stigma domains across the intervention period. Trained interviewers conducted and recorded all interviews in Vietnamese. The recorded interviews were transcribed and a portion of the transcripts was translated into English.

### **Process Data: Training Evaluations** and Monitoring Visits

ISDS interviewed members of the PMU during quarterly visits and monthly phone calls to obtain process data using a structured monitoring checklist. The checklist included questions on number and type of intervention activities, level of participation in those activities, and specific challenges in developing and implementing activities at the community level and how they were resolved. These data were later transferred into spreadsheets for analysis.

Table 2: Sample Sizes of Quantitative Survey at Baseline and Endline<sup>8</sup>

	Baseline		Endline	
	Cai Khe Cam Dong (Can Tho) (Quang Ninh)		Cai Khe (Can Tho)	Cam Dong (Quang Ninh)
Number of community residents	695	697	704	692
Total	1,392		1,3	396

The response rate at baseline was 91 percent and 90 percent at endline. The majority of non-respondents were either not found, or ineligible because of age or residency status. Refusals were low (two at baseline, nine at endline).

The sensitization workshops (provincial and community level) and training-of-trainers sessions held at the provincial level were evaluated with a pre- and post-training questionnaire that included both closed and open-ended questions. The questionnaires were designed to assess achievement of key training objectives and obtain feedback on the sessions.

### **Stigma Measures**

- (1) Awareness. Being able to name the issue is a first step toward building awareness and understanding of stigma. The survey assessed respondents' awareness by asking if they had heard of the word stigma (ky thi), and for those who had, assessed their comprehension of the word by asking them to provide specific examples of stigma.
- (2) Fear-driven stigma. In the survey, a series of previously validated items [48, 49] and new items specific to the Vietnamese context were used to measure fear-driven stigma [2]. These items capture both the underlying specific fear that may drive avoidance in a given casual encounter (e.g., fear of becoming infected with HIV through contact with sweat, leading to avoidance of any physical contact with a person with HIV), as well as the types of specific daily living activities around which fear of transmission occurs (e.g., sharing a toilet or hospital room with a person living with HIV, having a manicure or haircut, going to the dentist). Principal components factor analysis of these items yielded two factors. Based on this, two indices were constructed representing fear of casual contact (seven items) and fear of situations with the potential for contact with blood through sharp instruments (three items). Internal consistency reliability was high for both indices, with Cronbach's alpha values greater than 0.8 observed. (See Appendix C for details.) Indices were standardized to have a mean of 50 and a standard deviation of 10. Each point on the scale represents one-tenth of a standard deviation and point differences of three to five are considered significant based on standard guidelines for interpreting psychosocial indices [50]. Scores range from 0 to 100 with higher scores representing more stigmatizing responses.9
- (3) Value-driven stigma was assessed quantitatively through a series of attitudinal questions about blame toward people living with HIV and shame associated with having HIV. Principal components factor analysis of these items yielded one factor (seven items) that demonstrated high internal consistency reliability (alpha =.68 at baseline and .73 at endline). (See Appendix C for details.) As described for the fear-driven indices, items

were standardized to create a value-driven score for each respondent.

(4) Anticipated stigmatizing behavior. General population survey data have a fairly limited ability to capture change in behavior toward people living with HIV, and only can provide information on future intentions to engage in stigmatizing behaviors. 10

Because of these limitations the survey questions for this particular outcome focused on intentions, specifically what the respondent would do if faced with three potential daily life interactions with a person living with HIV. These were chosen as they represented commonly described stigmatizing situations experienced by people living with HIV in Viet Nam [2]. Specifically, the questions asked respondents to consider what they would do if they found themselves: (1) sitting next to someone in a tea or food shop they know or suspect is HIV-positive; (2) sharing an in-patient hospital room with someone they know or suspect is HIV-positive; and (3) buying food from a vendor they know or suspect is HIV-positive, but is not showing any physical symptoms of being ill.<sup>11</sup>

For each situation, we assessed respondents' intention to engage in stigmatizing versus non-stigmatizing behavior. In the tea or food shop scenario, those who reported that they would *do nothing* were coded as having the intention to engage in *non-stigmatizing behavior*. Respondents who had reported that they would either: move their seat, ask the person to change places, or leave the shop were coded as having intention to engage in *stigmatizing behavior.* For the hospital room scenario, respondents who reported that they would ask to change rooms, ask to remove the person with HIV, or ask to be discharged were coded as reporting intention to engage in *stigmatizing* behavior. Respondents who reported that they would do nothing were coded as reporting intention to engage in *non-stigmatizing behavior*. In the scenario around buying food, those who reported they would not buy food were coded as reporting to engage in *stigmatizing* behavior.

The use of standardized scores simplifies data analysis and interpretation of findings [51]. In addition, standardized scores do not suffer from floor and ceiling effects, which are potential problems for unstandardized additive indices [52].

<sup>10</sup> It is not feasible to capture this information directly in a survey of the general population for several reasons [53]. To begin with, it is not ethical to ask respondents if they themselves have experienced stigmatizing behavior, as this would necessitate them disclosing their own, or a family member's HIV status to the interviewer. Asking respondents if they themselves have engaged in stigmatizing behavior toward others is not likely to elicit reliable responses due to social desirability bias, that is respondents' tendency to provide the answer they think appropriate, rather than what is true. Lastly, in a population with low HIV prevalence, an extremely large survey sample would be required to capture enough respondents who have had the opportunity to engage in such behaviors during the intervention period.

<sup>11</sup> The question specifies a person living with HIV showing no outward signs of illness because other research [54], as well as evidence from this study, shows that there is a significantly different response to this question if the person with HIV shows outward signs of illness.

### **Data Analysis**

Analysis was conducted separately by community (province) because of the many differences between them, including socio-economic differences and differences in exposure to HIV programs and messaging prior to the start of this intervention. In addition, Cam Dong has a higher HIV prevalence and a differing degree and duration of experience with injecting drug users than Cai Khe.

### Quantitative data

The team identified key variables to measure stigma (focusing on the three key drivers of stigma and stigmatizing behaviors); exposure to intervention activities; socio-demographic variables, such as age, sex, and regional residence; and other factors that might affect stigma, including (1) knowing a person living with HIV and (2) exposure to messages about HIV and stigma in print, visual and audio media. The analysis focused on examining change in stigma over the intervention period and whether there was a relationship between any observed change and the intervention activities.

The analysis first examined whether change in stigma had occurred over the intervention period. This was done by comparing values on individual items between baseline and endline in the four key outcome areas of interest and then examining changes in mean scores on the fear- and value-based stigma indices. Change over time was assessed by testing differences between baseline and endline proportions using Chi-square tests of independence (dichotomous measures) and t-tests (continuous measures).

The analysis then focused on examining the effect of the project activities on stigma by comparing endline survey respondents who reported being exposed to specific intervention activities with those who reported no exposure (Cai Khe) or little exposure (defined as either no exposure, or exposure to one activity) (Cam Dong). In Cam Dong, the rate of exposure to at least one project activity was so high (95 percent) that there were too few respondents in the category of "no exposure" to allow for a meaningful comparison. Hence, exposure to no activities and exposure to one activity were collapsed into one category, which served as the reference category for the regression analyses in Cam Dong.

Ordinary least squares regression was used with continuous outcome measures and logistic regression for the dichotomous outcomes, controlling for other factors besides program activities (e.g., age, sex, exposure to media, knowing a person living with HIV) that might influence the stigma outcomes of interest (e.g., awareness, fear and value-driven stigma, anticipated behavior).

To allow for comparison between the two communities, the analysis was restricted to the following four main intervention activities that were carried out in both communities:12

- (1) Distribution of an HIV and stigma fact sheet;
- (2) Household visits by community educators;
- (3) Community sensitization meetings; and
- (4) Community billboards.

### **Qualitative** interviews

An analytical framework was developed to guide the analysis of interview data. The framework was based on key emerging themes in the transcripts and key evaluation areas of interest (e.g., awareness, fear- and value-driven stigma, stigmatizing behavior, and exposure to project activities). A matrix was used as the main analytical tool in organizing text by corresponding thematic areas. This matrix was then summarized for each key theme.

### **Evaluation Results**

This section of the report begins with a brief overview of the respondents' characteristics, the sample's exposure to intervention activities, and the key causes of stigma in the study communities. The remainder of the section focuses on the key stigma outcomes of interest in the evaluation: the three immediately actionable causes of stigma, and stigmatizing behavior (discriminatory actions). For each of these key outcomes of interest, we briefly discuss the situation in the communities before the intervention began, as documented in baseline data. Next, baseline and endline data for key indicators are presented and finally the results of multivariate analysis of endline data to examine the relationship of the intervention activities to stigma.

### **Profile of the Sample**

Respondents varied in age from 18-70, with more than 50 percent female (50.4 baseline, 53.5 endline). The majority of respondents were married (with slightly more at endline—75 percent, than baseline—69 percent). Eight percent (baseline) and 6 percent (endline) were divorced, widowed or separated; and between 23 percent (baseline) and 19 percent (endline) never married. The majority of the population had some high school education or higher (some junior high—36 percent baseline, 35 percent endline; some high school—38 percent baseline, 43 percent endline; more than high school—19 percent baseline, 17 percent endline), and less than 10 percent had less than a completed primary education (7 percent baseline,

<sup>12</sup> The school-based activities that were implemented in both communities were excluded because only those households with children enrolled in the target schools would have been exposed to them.

6 percent endline). The majority of respondents fell into a medium socio-economic status (SES) at endline in both communities (80 percent Cam Dong, 72 percent Cai Khe) as assessed by an additive index of household items at endline.13

### **Exposure to the Intervention**

Intervention coverage at the community level was high: 94 percent of community survey respondents in Cam Dong reported exposure to at least one activity, and 85 percent reported similar exposure in Cai Khe. Figures 1 and 2 show coverage in more detail, both in terms of exposure to total number of activities as well as exposure to the four principal intervention activities implemented by both communities.

### **Stigma Outcomes of Interest**

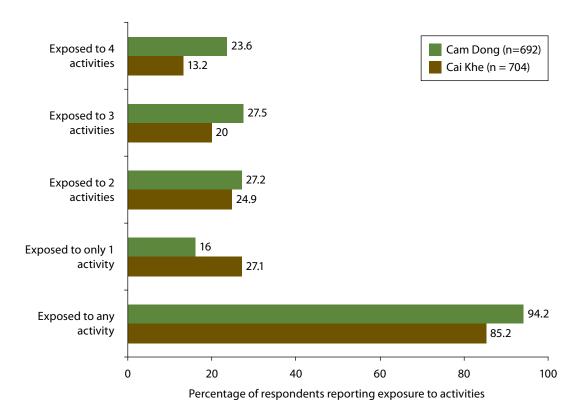
Consistent with the findings of an earlier phase of the larger study [2], as well as other studies [11, 37], it

appears that the key underlying causes of HIV stigma in Cam Dong and Cai Khe communities are lack of awareness of stigma; fear of infection, primarily through everyday casual contact; and judgments made about the moral character of people living with HIV, resulting in blaming people with HIV for their situation, and people with HIV feeling shame as a result. The intervention activities focused on addressing these three causes as well as people's stigmatizing behavior (discriminaton). The evaluation results presented below focus on examining changes in: (1) awareness of stigma; (2) fear-driven stigma; (3) value-driven stigma; and (4) stigmatizing behaviors over the intervention period, and the relationship of intervention activity participation to stigma at endline.

### (1) Awareness of stigma

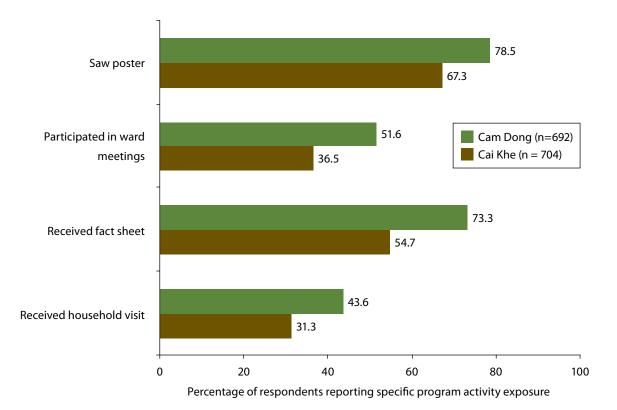
Being aware of the presence of HIV-related stigma and being able to characterize it accurately is an important first step in addressing stigma among individuals and communities. It was encouraging to note that people interviewed at baseline in both communities generally were aware of the concept of stigma, that it is prevalent, and that it needs to be reduced. However, fewer baseline respondents understood clearly how stigma manifests and the specific actions they could take to reduce it.





<sup>13</sup> Items used were: color TV, landline telephone, cell phone, fridge, motorcycle, car, air conditioner. Respondents who possessed two items or less were categorized as "low SES"; respondents who possessed three or four items were categorized as "medium SES"; and respondents who possessed between five and seven items were categorized as "high SES."

**Figure 2: Exposure to Specific Intervention Activities** 



The survey data measured awareness in two ways. The first was by asking the question, "Have you heard of the word ky thi (stigma)?" Recognition of the word for stigma significantly increased over the intervention period (baseline to endline), from 40 percent to 70 percent (p<.001). In Cam Dong, recognition of the word for stigma more than doubled, increasing significantly from 38 percent to 83 percent (p <.001), while in Cai Khe there was a slightly smaller, but equally significant (p<.001) increase from 42 percent to 57 percent.

While having heard the word is an important first step in building awareness, the next step is to understand the various expressions and consequences of stigma. In the survey data, understanding was measured by asking respondents who replied that they had heard of the word for stigma to provide specific examples. More respondents were able to provide correct examples after the intervention than at baseline. For example, respondents' mention of situations involving isolation (e.g., complete avoidance of people living with HIV) and blame as examples of stigma significantly increased (p<.001). Conversely, the proportion of respondents who had heard of stigma but could not provide an example declined significantly in Cai Khe from 20 percent to 4.5 percent (p<.0001), though there was no decrease in Cam Dong. 14

After the intervention, the number of respondents who were able to give multiple correct examples of stigma also increased significantly (Figure 3), showing an increase in depth of understanding of the multiple forms stigma takes. However, a small proportion of respondents still provided incorrect answers of what stigma is (16 percent Cam Dong, 4 percent Cai Khe), indicating a continued need for efforts to build awareness of stigma in these communities.

The qualitative data also show change from baseline to endline in awareness around stigma and discrimination. Mirroring the survey data, ability to describe stigma and provide concrete examples of stigma emerged in the endline qualitative data. As this young man explained:

When I stigmatize against HIV-infected people, it means that I keep away from them; I fear them and I do not want to contact them. And about discrimination, I only make friends with the HIV non-infected people, but not with the infected ones. I think that is discrimination. Last year, I did not know much about HIV and AIDS. Since my involvement here, I have acquired more knowledge about HIV because I often talk with the ward staff, read leaflets and newspapers, watch TV and listen to the local speaker. (Focus group, Endline, Male, Cai Khe)

In addition, at endline respondents showed more awareness not only of what stigma is, but also that it should be reduced and why. People became more aware that

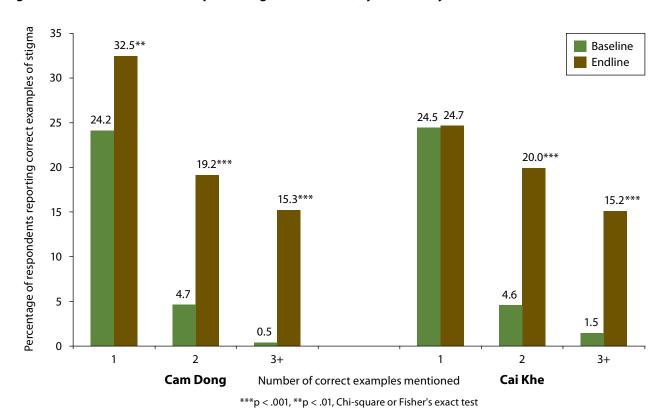
<sup>14</sup> The baseline figure was already low in Cam Dong at 9 percent. (See Table 3.)

Table 3: Examples of Stigma Provided by Respondents Who Had Heard of Stigma, Baseline and Endline (Percent Reporting Yes)

Item name	Cam Dong		Cai	Khe
	Baseline (n=245)	Endline (n=569)	Baseline (n=262)	Endline (n=403)
Isolation	60.4	61.7	44.3	71.5 ***
Blame	7.3	17.2***	1.5	16.1***
Discrimination	2.0	17.2***	10.3	20.8***
Rumor	1.2	3.3	0.0	7.2***
HIV is a social evil	7.8	3.2**	4.6	2.2
Could not provide an example	8.6	9.3	20.6	4.5***

<sup>\*\*\*</sup> p≤ .001; \*\*p≤.01, Chi-square test of independence

Figure 3: Number of Correct Examples of Stigma Mentioned, by Community Site



isolating people living with HIV and their families is not helpful, and that HIV is a health condition, not a "social evil." They also perceived that project activities led to changes in stigmatizing behaviors in the community.

A number of residents attended the sensitization workshop. After this process, it was clear that it [stigma] reduced among people. Community people and people living with HIV and their families have more sociable attitudes. People living with HIV and family members and other people meet and communicate with each other in a more open-hearted way. (Focus group, Endline, Male, Cam Dong)

To assess the relationship between the intervention activities and this increase in awareness of stigma, logistic regression analysis was conducted at endline on the effect of exposure to intervention activities on having heard the word for stigma. Table 4 presents the odds ratios for the main variable of interest—number of intervention activities exposed to—while controlling for individual background characteristics (e.g., sex, age, education, SES, marital status); exposure to HIV or stigma messaging in radio, print or TV media; and knowing a person living with HIV. In both communities, being exposed to project

activities increased the odds of having heard of stigma, with a clear dose-response pattern evident. That is, the more activities a respondent reported exposure to, the more likely he or she was to be aware of the word ky thi.

The activity exposure level at which this relationship became statistically significant differed by community. In Cai Khe, a statistically significant difference in awareness (compared to no exposure) occurred at exposure to two or more activities, while in Cam Dong (compared to 0 or one exposure) it occurred at exposure to three or more activities. The strength of the relationship also differed between the two communities. For example, in Cam Dong, respondents exposed to four activities were 3.3 times as likely as those with minimal exposure to be aware of stigma (p≤.01), whereas in Cai Khe, respondents exposed to four activities were almost eight times as likely as those exposed to no activities to be aware of stigma  $(OR=7.78, p \le 001).$ 

### (2) Fear-driven stigma

While some baseline participants were well informed about HIV transmission, the baseline data show that stigma stemming from fear of contracting HIV through casual contact persists and is common. At baseline, 60 percent of respondents reported that they feared contracting HIV through at least one of six casual contact items and this general fear was a recurrent theme expressed in the baseline qualitative data. As a female baseline focus group participant in Cam Dong explained:

*I could not dare to drink from a cup poured by the infected* person because I did not know whether I could be infected or not. When I come to visit that person's house I would sit for a while and go home but I could not drink when I was offered a drink. Even when the person died from the disease [AIDS]

people did not dare to get close. People avoided, they did not dare to enter when they came to attend the funeral.

At baseline, HIV often was perceived as a highly contagious, easily transmitted and deadly virus. Considerable ambiguity about the ways in which HIV can be transmitted "through blood" also was observed, with baseline respondents expressing a prevailing uncertainty and continued doubt and fear about the routes and risks of transmission, despite "knowing" how HIV is transmitted. Even within affected families and among people living with HIV, inaccurate information, lack of clarity and uncertainty persisted at baseline. The following excerpt from a female baseline focus group participant in Cai Khe is illustrative of this:

For example, if they [people living with HIV] sell food or cold drinks, they sell the fully cooked stuff, so there is no need to worry about the food. But, in fact, it is rather scary eating those foods.

These fears led many respondents to keep their distance from, isolate or discriminate against people living with HIV. The following quote from a young man living with HIV in Cam Dong at baseline shows how fear can lead to stigma:

[My sister] helps with the cooking only and she dares not wash my clothes. She is afraid of being infected; she keeps away from me and looks down on me.... [my siblings] keep away for fear of contagion.

A female focus group participant in Cai Khe summed the situation up well, explaining that what is needed is not just more information about HIV transmission risks, but better information:

It is said that the disease is not too easily transmitted, only transmitted through blood transfer or sexual activities; it is not transmitted through contact. I know roughly, but I am

Table 4: Results of Logistic Regression of Level of Exposure to Project Activities on Awareness of Stigma (Heard of the Word Ky Thi)

	Cam Dong (n=692)	Cai Khe (n =704)
	Adjusted Odds Ratio (CI)	Adjusted Odds Ratio (CI)
Number of Activities Exposed to		
None	NA	Ref.
None/one	Ref.	NA
1	NA	1.70 (.95, 3.05)
2	1.11 (.64, 1.91)	2.55 (1.40, 4.64)**
3	1.92 (1.05, 3.50)*	4.65 (2.47, 8.78)***
4	3.30 (1.53, 7.1)**	7.78 (3.64, 16.63)***
Constant	.16*	.09***

<sup>\*\*\*</sup>p \le .001; \*\*p \le .01; \* p \le .05

Note: Logistic regression controls for age, sex, media exposure, proximity, education level, marital status, and socio-economic status (SES).

Table 5: Percent of Respondents Reporting Fear of Infection with HIV through Casual Contact

Item Name (Fear of infection with HIV through)	Cam Dong, Quang Ninh		Cai Khe,	Can Tho
	Baseline (n = 697)	Endline (n = 692)	Baseline (n=694)	Endline (n=703)
Exposure to saliva of a person with HIV	18.7	21.8	37.2	39.7
Exposure to excreta of a person with HIV	35.3	27.2**	44.5	42.0
Exposure to sweat of a person with HIV	10.2	10.8	25.5	25.2
Sharing in-patient room with a person with HIV	34.1	25.6***	52.3	43.7**
Sharing a toilet with a person with HIV	16.0	10.0**	47.3	35.8***
Shaking hands with a person with HIV	6.9	6.2	17.1	16.4
Going to a dentist	82.1	68.7***	84.7 (n=693)	80.5* (n=702)
Having a haircut	68.4 (n=696)	60.3**	59.5	59.0
Having a manicure	77.8 (n=695)	61.3***	88.3	76.8***

<sup>\*\*\*</sup>p≤.001; \*\* p≤.01; \*p ≤.05

still afraid. Now I would like to have more practical and clearer information to help people understand more deeply. Because some are still worried about the disease. If we want people to stigmatize less, we need the specific information.

Both qualitative and survey data were analyzed to examine changes in fear-driven stigma over the intervention period. Table 5 shows the baseline and endline percentages of respondents reporting any fear. 15 The proportion of respondents expressing fear of HIV infection in a given situation varied widely at both baseline and endline. For example, while at baseline only 7 percent of respondents in Cam Dong feared infection from shaking hands with a person living with HIV, 82 percent feared infection from visiting a dentist. In general, more fear was associated with situations in which a respondent might come into contact with bodily fluids. Respondents were most fearful of everyday situations in which sharp implements are used that could lead to contact with blood.

In both communities, fear of infection through casual contact reduced significantly after the intervention. In Cam Dong, fear decreased significantly for six of the 10 items, and in Cai Khe, fear reduced for four of the 10 items (Table 5). Respondents in both communities reported less fear of infection through sharing an in-patient room, sharing a toilet, going to the dentist and having a manicure. It should be noted that fear of infection was greater in Cai Khe for all but one situation at baseline. No change in fear was observed in either community for three items (exposure to saliva, exposure to sweat and shaking hands with a person living with HIV); however, these situations also were the least feared at baseline.

Table 6 shows the adjusted linear regression results for the first index (the first seven items in Table 5), which measures fear of casual contact in daily life. In general, the more project activities a respondent was exposed to, the lower the score on the "fear of casual contact" index, reflecting less fear of HIV infection through casual contact. Consistent with the findings around awareness of stigma, exposure to a higher number of activities was needed in Cam Dong (three or more) to see a significant decrease in score on the fear of casual contact index. On average, respondents exposed to three activities scored 2.9 points (p≤.01) lower on the fear index compared to those exposed to 0 or one activity, while those exposed to four activities scored 3.2 points (p≤.01) lower. <sup>16</sup> A dose response also was observed in Cai Khe, and significant reductions began already with exposure to one activity and grew larger as activity exposure increased. On average, respondents exposed to one, two, three and four activities scored 4.3, 5.0, 5.8 and 7.1 points lower

To assess the influence of the intervention activities on respondents' fear of HIV infection through casual contact, linear regression was used to predict respondents' scores on two separate fear indices after controlling for other factors that could influence change in stigma. These two indices, generated through factor analysis (see Research Methods section under Stigma Measures), reflect two main categories of fear, which also were apparent in the baseline qualitative data: fear of acquiring HIV through everyday contact within the household or community, and fear of acquiring HIV in common situations with potential for blood contact (for instance, exposure to blood on sharp tools or instruments such as razors, scissors or nail trimmers at the barber or beauty salon).

<sup>15</sup> The four possible response categories were: 1) no fear; 2) a little fear; 3) some fear; and 4) much fear.

<sup>16</sup> As noted in the methods section, a three to five point difference in the index is considered significant.

on the fear index, respectively, than those exposed to no activities.

Table 7 presents the results of the linear regression for the index relating to fear of exposure to everyday living situations with perceived potential for blood contact (last three items in Table 5). As with the fear of casual contact index, exposure to three or more activities was needed to significantly reduce scores in Cam Dong. In Cai Khe, exposure to all four activities was needed to see a significant decrease in the score on this index.

The endline qualitative data confirm that the interventions had a meaningful impact on reducing the fear-related dimensions of HIV stigma, particularly casual contact not involving any chance of blood contact on sharp instruments. Respondents clearly noted that they now felt less fear in sitting and talking, shaking hands,

sharing meals and dishes, and maintaining close relationships with people living with HIV. Respondents were much more confident after the intervention about how HIV is *not* transmitted, and this confidence translated into a greater degree of acceptance of people living with HIV and their family members. The following quotes illustrate this finding:

Before last June, I did not know what the modes of HIV transmission are, so I was afraid whenever meeting a sick and skinny person; I did not talk with him. I did not know whether talking with, or contacting or shaking hands with HIV-infected people or their breath, like tuberculosis, have any risk of infection, so I was so afraid. Now, I know, I understand...I talk with them, sit near them, or sit on their bed, no problem...I understand that [HIV] is not transmitted that way, so I do not need to be afraid anymore. (Focus group, Endline, Female, Cai Khe)

Table 6: Results of Linear Regression of Level of Exposure to Project Activities on Fear of Casual Contact

Characteristics	Cam Dong (n=691)	Cai Khe (n=702)	
	Adjusted β coef.	Adjusted β coef.	
Number of Activities Exposed to			
None	NA	Ref.	
None/one	Ref.	NA	
1	NA	-4.34**	
2	-1.55	-4.98***	
3	-2.88**	-5.81***	
4	-3.19**	-7.13***	
Constant	54.02***	57.41***	

<sup>\*\*\*</sup>p ≤.001; \*\*p ≤.01

Note: Linear regression controls for age, sex, media exposure, proximity, education level, marital status and socio-economic status (SES).

Table 7: Results of Linear Regression of Level of Exposure to Project Activities on Fear of Blood (Sharps) Index

Characteristics	Cam Dong (n=691)	Cai Khe (n=702)	
	Adjusted β coef.	Adjusted β coef.	
Number of Activities Exposed to			
None	NA	Ref.	
None/one	Ref.	NA	
1	NA	38	
2	-2.11	-1.16	
3	-2.49*	-1.07	
4	-2.36	-3.94*	
Constant	44.28***	51.23***	

<sup>\*\*\*</sup>p ≤.001; \*p≤<.05

Note: Linear regression controls for age, sex, media exposure, proximity, education level, marital status and socio-economic status (SES).

Before I was sensitized I did not understand, so I was afraid of HIV infection. When people sensitized us about antistigma towards HIV-infected persons I opened my mind. Previously, to be frank, I was afraid to hear about HIV infection.... Before when I did not understand, I thought that if I lived with an HIV-infected person I would become infected as well. Now I know I cannot be infected when living together with a person infected with HIV. (Focus group, Endline, Female, Cam Dong)

Despite the encouraging evidence that fear of transmission through causal contact has reduced, some uncertainty regarding blood-related risk remained, for example, the risk of transmission through getting a manicure or a haircut.

It was said that it [HIV] is transmitted only through three channels. One is sexual, second is blood and third is sharing needles while injecting drugs. It is not transmitted when we communicate face to face, shake hands or talk. But we should remember carefully that sharing a toothbrush could be infectious. It is also infectious if we share our nail clippers. So we should avoid sharing those; otherwise we can communicate with them [people living with HIV] normally. (Focus group, Endline, Female, Cai Khe)

There are many cases that may happen unexpectedly. For example, we and our children are not infected, but who knows? It may happen, for example, if someone goes to have ear-pick, or haircut, or lips and eyes tattooed. We are old but we have to remind our daughters and daughters-in-law that they should be careful if they use such services—they may get risk of infection. My son and my husband should choose a very trustful haircut shop because there are various people going for haircut. It would be good if one takes precautions, that's all. (In-depth interview, Endline, Female, Cam Dong)

People continued to feel particularly unsafe about having contact with a person living with HIV when their hands have some open cuts or scratches. Avoidance in such cases is justified as a "preventive measure." As the mother of a young man living with HIV in Cai Khe confided at endline:

As my son P. got the disease [HIV], we should take precaution. We can eat and drink together, but we should not share combs, towels or nail clippers. We share meals and the bathroom. Something that may be infectable, for instance, a cut finger, we should be careful about.

### (3) Value-driven stigma: shame, blame and judgment

A third important cause of HIV-related stigma is the widespread disapproval of illegal drug use and commercial sex—behaviors widely known in Viet Nam as "social evils" and linked to HIV in the minds of many. The baseline qualitative data show how HIV stigma stemming from moral judgment is intimately connected with the problem of injection drug use, the perception of drug use as a "social evil" and of drug users as lacking in

moral rectitude. This was true in both communities, but particularly in Cam Dong, which has a longer history of injection drug use and a higher prevalence of users living in the community. The father of a young man living with HIV in Cam Dong shared his point of view at baseline, which demonstrates the strength of the linkage between moral character and HIV in people's minds:

As I understand it, HIV and AIDS means that young people used to play too much, engaged in drugs, and lost their own point of view, so they fell into addiction, got spoiled.

The link between HIV and sex work also was present, although less pronounced. As a male baseline focus group participant in Cai Khe explained:

Being in that situation [having HIV] means bad. That person is the one who sleeps around and leads an indecent way of living so their morals are not good.

The baseline survey data indicates how widespread these connections are, as well as the judgment, shame and blame that result. For example: 61 percent of survey respondents agreed with the statement, "People living with HIV are promiscuous"; 77 percent agreed that people living with HIV should "bear the consequences of their bad behavior"; and more than 90 percent agreed with the statement that drug users (and 87 percent that prostitutes) "are to blame for spreading HIV in our community." The presence of blame is summed up by this female baseline focus group participant in Cam Dong:

Those persons [people living with HIV] are to blame...as they do not respect even themselves and [that] leads to HIV infection.

The strength of these connections between HIV and "immoral" behavior such as drug use and the resulting assumptions about a person's (and often their family's) moral character is demonstrated in this quote from a young woman living with HIV in Cai Khe who, when asked at baseline whether she sometimes attends the health center for care and support, responded:

Rarely. Because there are a lot of drug users in my sector and therefore there are a lot of HIV-infected people who often come here. I don't want to meet them. I am different from them. They are over self-indulgent and not married while I am married, so I have to support my family.

Illustrating change in value-driven stigma over the intervention period, Table 8 presents the percentage of respondents reporting any level of agreement with the seven items used to measure value-driven stigma at baseline and endline. High levels of blame toward people living with HIV, injecting drug users and sex workers, as well as shame surrounding living with HIV existed at baseline. More than 90 percent of those surveyed agreed that "HIV and AIDS is a social evil" and "Injecting drug users are to blame for spreading HIV in our community." The proportion of respondents agreeing with each statement reduced significantly at endline. However, it remains unacceptably high in both communities, with more than 40 percent of respondents agreeing with each stigmatizing statement.

To assess the influence of the intervention activities on value-driven stigma, linear regression was used to predict respondents' scores at endline on the seven-item value-stigma index, after controlling for other factors that could also influence stigma. Table 9 shows the adjusted linear regression results. Similar to what was observed for the fear indices, the more stigma-reduction activities a respondent was exposed to, the lower the score on the value-driven stigma index in both communities, indicating less value-driven stigma. A dose-response pattern was observed for both communities, but was stronger in

Cai Khe. Both communities required exposure to three or more activities to see a statistically significant difference in the stigma-score relative to those exposed to no activities (Cai Khe) or 0-1 activities (Cam Dong). These decreases were moderate in size (almost three points) and in significance ( $p \le .05$ ), relative to outcomes around awareness and fear.

The qualitative data also suggest change in the way community members thought about people living with HIV after the intervention. Participants in the mid-term evaluation and endline survey had better attitudes, more tolerance and greater sympathy toward people living with HIV than at baseline, as the following quotes indicate:

Table 8: Value-Driven Stigma: Percent of Respondents Reporting Agreement with Stigmatizing Statements

Value statement	Cam Dong		Cai	Khe
	Baseline (n=697)	Endline (n=692)	Baseline (n=695)	Endline (n=704)
Prostitutes are to blame for spreading HIV in our community	87.8	75.0***	87.0 (n=694)	74.0***
I would be ashamed if someone in my family had HIV/AIDS	48.0 (n=696)	41.8*	64.7 (n=694)	48.4***
People living with HIV should bear the consequences of their bad behavior	78.5	64.5***	74.8 (n=694)	68.6* (n=703)
HIV/AIDS is a social evil	92.4 (n=696)	76.1*** (n=691)	93.9 (n=693)	82.9*** (n=703)
Injecting drug users are to blame for spreading HIV in our community	92.7	73.7***	90.8 (n=694)	83.8***
People living with HIV are promiscuous	48.1	41.6*	73.9 (n=693)	65.8**
People living with HIV are to blame for bringing HIV into our community	71.9 (n=691)	47.7***	77.5 (n=693)	67.5***

<sup>\*\*\*</sup>  $p \le .001$ ; \*\* $p \le .01$ ; \* $p \le .05$ , Chi-square test of independence

Table 9: Results of Linear Regression of Level of Exposure to Project Activities on Value-Driven Stigma

Characteristics	Cam Dong (n=691) β coef.		
	Adjusted	Adjusted	
Number of Activities Exposed to			
None	NA	Ref.	
None/one	Ref.	NA	
1	NA	-2.46	
2	-1.03	-1.77	
3	-2.65*	−3.58*	
4	-2.71*	-3.89*	
Constant	46.56***	50.72***	

<sup>\*\*\*</sup>p ≤.001; \*p ≤.05

Note: Linear regression controls for age, sex, media exposure, proximity, education level, marital status and socio-economic status (SES)

This [HIV] was brought by social evils—they did not want it themselves. Their families did not want it but the societal reality influenced much on them, they themselves cannot anticipate that problem. Life circumstances pushed them into it. Now that the thing is done and is not reversible we have to help them and should not avoid them. We should help them without question. (In-depth interview, Mid-term, Male, Cam Dong)

After [receiving] education and communication [messages], people understand that HIV is not social evil but a disease. This has changed the community's perception. For instance, that man may not be HIV-infected because of sex work but maybe because of an unfortunate love affair, or due to some unexpected circumstance. So not all HIV infections are due to social evils. In reality there are often extenuating circumstances. (Focus group, Endline, Female, Cai Khe)

While a strong association among HIV, drug users and social evils was observed at baseline and was still evident at endline, the fact that more respondents spoke about HIV as a disease rather than a social evil at mid-term and endline indicates that intervention activities, including efforts to de-link HIV from social evils, have begun the process of change.

Now through education and communication, people changed their perception, they get consensus that people living with HIV should be assisted and stigma should be reduced in order to help people with HIV integrate into the community. People now identify that HIV is not social evil. We are against social evils but not the disease. A person who bears the disease has already suffered from pain and misery, they need sympathy. We have achieved consensus that we should help them. (Focus group discussion, Mid-term, Male, Cam Dong)

People view this as an unwanted accident, so they have more open attitudes, and are not as strict as before... After the education and communication activities here over the past year, it [stigma] has clearly reduced. (Focus group, Endline, Female, Cai Khe)

While these statements suggest that some respondents were able to disassociate HIV from the concept of "social evils," other respondents struggled to do so at endline. The following quote indicates the difficultly of shifting value-driven stigma:

Psychologically one cannot help not to stigmatize because people who have that disease were debauched ones. Women who live decently but get infected through their husband [on the other hand] are victims, and their lives have become miserable. How can we hate them? People do not sympathize with those girls who sell bia om [literally "beer and hugs"] but sympathize with those who are victims. But the person who passed the disease to his wife should not be forgiven, even if we should not stigmatize against him. (In-depth interview, Mid-term, Female, Cai Khe)

### (4) Stigmatizing behavior (enacted stigma or discrimination)

The manifestations of HIV-related stigma reported by participants at baseline included gossip, avoidance, stigmatizing attitudes and outright discrimination. The importance of gossip as a form of stigma was widely reported, the general consensus being that word travels fast, and that, though indirect, gossip can be painful and have potentially tragic consequences. The fear of gossip is exacerbated by the rate at which bad news travels in these communities. As one focus group participant in Cam Dong noted, "Vietnamese people have a saying that 'bad news has wings.' This [HIV] is very bad news." A male baseline focus group participant in Cai Khe described the process thus:

They did not [say rude things] to their face, but they gossiped behind their back, that if someone from that family had HIV, try to stay away from them. The rumors flew from one person to another, then to the whole community.

As the quote above indicates, secondary stigma—or stigma against family members and close contacts of the people with HIV—was also apparent in these communities at baseline. This sometimes had important consequences for household livelihoods, as will be discussed below. Survey data indicate that secondary stigma was particularly high in Cai Khe, where 47 percent of baseline respondents said they would not buy food from a vendor who has a family member living with HIV. This was in contrast to 9 percent of respondents in Cam Dong.

Avoidance was another common form of enacted stigma reported by study participants at baseline. Both people living with HIV and community members participating in focus groups explained this particular outcome of the fear and moral judgments made against people living with HIV and their families. The quote below is from an interview with a young person living with HIV in Cai Khe at baseline:

They keep away from me; it is inevitable that they stigmatize against me...they show their scornful attitudes to me; they laugh at me.... Their facial expressions show their hatred

The consequences of HIV and associated stigmas (against injecting drug users and sex workers) at baseline included the reported reluctance to disclose one's HIV status to others—including one's spouse and/or sexual partners and the reluctance to use available treatment, care and support services. Fear of disclosure and reluctance to access services often went hand in hand:

*I am afraid of coming here [to the health center]—more* people will learn of my HIV status and my in-laws will learn it too. I don't want to make my family-in-law worry about me. Please keep my HIV information secret! (In-depth interview, Baseline, Woman living with HIV, Cai Khe)

A second commonly discussed consequence of HIVrelated stigma was the effect it had on one's business, or the business of one's family. This may have been particularly true for people who sold cooked food, for whom an HIV diagnosis in the family could mean ruin. The mother of a young man living with HIV in Cam Dong described her circumstances at baseline. She used to sell cooked porridge from her home. When asked whether her business had dropped off since her son became sick, she said, "They are afraid of contagion so they dare not eat here." In fact the situation became so drastic that she had to move her business premises elsewhere—a space she then had to pay additional rent for. Even once she moved her shop, it took some time for business to resume.

The goal of addressing the three underlying drivers of stigma described above (lack of awareness, fear of contracting HIV through casual contact and value-driven stigma) was to change the stigmatizing behavior (discrimination) prevalent at baseline, and thereby reduce the stigma experienced by people living with HIV and their families. Change in stigmatizing behavior after the intervention was evident both in people's descriptions of their own actions and their observations of the actions of others. The most commonly reported changes were increased willingness to communicate openly, sit close to and eat and drink with people living with HIV, and attend funerals to pay respects without fear:

In general it is much different than before. Before, people did not dare to visit a house that had a person living with HIV; now they visit as normal, they contact as normal, talk as normal and eat as normal. They even share the same eating tray, drink alcohol together, no problem. Before, they even did not dare to visit my house. (In-depth interview, Endline, Man living with HIV, Cam Dong)

They [community members] did not dare to talk or shake hands with people living with HIV [before the interventions]. After participating in meetings on HIV, they now are no longer afraid of such behaviors. (Focus group, Endline, Female, Cai Khe)

An educator in Cam Dong explained how he overcame his own stigma and fear to help a neighbor suspected of having HIV:

Before the project, when I met an HIV-infected person who was bleeding, I was so afraid. Now after being involved in the project I myself have given first aid to my neighbor. He was lying on his bed, foaming in his mouth with blood. I asked his wife to wipe out the blood, and I massaged him and gave first aid. I helped him twice. He always said that he would die without my help. (Focus group, Endline, Male, Cam Dong)

Change also was evident in the testimonies of people living with HIV and their family members who observed and felt these changes in their daily interactions with community members. In interviews, people living with HIV confided that community members care for and communicate with them more openly, helping them to feel more confident and less inferior. In some cases, simply knowing that anti-stigma activities were being carried out in the ward made a difference.

*I do not know about other persons but in my case many* people care for me. Because this project came to the ward and educated people, people understand more compared to previous year...they have less stigma toward those with HIV. Residents, the head of clusters and units attended the education meetings, and they become educators to other people. For example, in my club, women attended meetings then in their turn they educated other persons. So residents now do not stigmatize as strongly as before. It is not that stigma ended totally, stigma still exists, but...not all people stigmatize against HIV. (In-depth interview, Endline, Female living with HIV, Cam Dong)

These changes had important practical benefits for people living with HIV and their families: Businesses were salvaged as clientele once again felt safe in frequenting tea shops and eateries run by HIV-affected people, and people living with HIV experienced a greater feeling of acceptance and welcome within their communities. As this woman in a focus group discussion in Cai Khe described:

In this sector, there is a family trading in banh trang [griddle cakes]. This family has a member who has HIV. Being worried about the risk of infection, fewer and fewer people bought their cakes and then that family had to close their shop. Before the [project's intervention], people were very frightened; they dared not use the food sold by that family with an HIV-infected person. Now, that family can open their shop again. (Focus group, Endline, Female, Cai Khe)

While the qualitative data provide a rich source of information on actual behavior in the community and how it changed over the intervention period, the survey data only can capture future intentions to engage in stigmatizing behaviors. The survey asked three questions on what the respondent would do if faced with three common daily life interactions with a person living with HIV. Specifically, the questions asked respondents to consider what they would do if they found themselves: (1) sitting next to someone they know or suspect is HIV-positive in a tea/food shop; (2) sharing an in-patient hospital room with someone they know or suspect is HIV-positive; and (3) buying food from a vendor they know or suspect is HIV-positive, but is not showing any physical symptoms of being ill. We compared respondents' intention to engage in stigmatizing versus non-stigmatizing behavior in each situation.

Table 10 provides the percentage of respondents reporting intention to engage in stigmatizing behavior at baseline and endline. For all three scenarios, the intention to engage in stigmatizing behavior decreased significantly from baseline to endline in both communities. For example, the intention to engage in stigmatizing behavior in a tea or food shop decreased by 12 percentage points in both communities (p<.001). A larger proportion of respondents in Cai Khe indicated an intention to engage in stigmatizing behavior in all three situations than those in Cam Dong at both time points.

To further examine the relationship between reductions in intention to stigmatize and project activities at endline, logistic regression analysis was conducted for each of these items, controlling for socio-demographic characteristics, exposure to HIV and stigma messages in the media, and proximity to a person living with HIV. Tables 11 and 12 show the results of this analysis. Similar to the other outcome variables examined, in Cam Dong (Table 11) a dose-response pattern was observed in the relationship between exposure to project activities and stigma. As the number of activities a respondent was exposed to increased, the odds of reporting intent to engage in stigmatizing behavior declined steadily. However, exposure to three or more activities was needed to see a significant difference in intention to engage in stigmatizing behavior.

The pattern observed in Cai Khe (Table 12) is slightly different. Exposure to project activities led to significant declines in intention to engage in stigmatizing behaviors for all three situations, even with exposure to just one project activity. However, the dose-response was less clear than in Cam Dong. Instead of the odds of reporting intention to engage in stigmatizing behavior steadily decreasing with each increase in exposure level, exposure to one and two activities have around the same effect on the odds, as do exposure to three and four activities, with the dose-response (a drop in the odds) occurring between these two groups (1-2 and 3-4).

Project activities clearly have helped reduce intention to engage in stigmatizing behavior in both communities, and as a general rule, the more activities a person is exposed to, the greater the reduction in intention to engage in stigmatizing behavior. That the reported intention translates into actual changes in behavior is supported by the qualitative data described above, which documents one's own and observed changes in behaviors by endline respondents, as well as reported reductions in the experiences of stigma by people living with HIV and their families.

Table 10: Percentage Reporting Intention to Engage in Stigmatizing Behavior

% reporting intention	Cam Dong, Quang Ninh		Cai Khe,	Can Tho
	Baseline	Endline	Baseline	Endline
In a tea or food shop	18.0 (n=693)	5.6*** (n=627)	33.7 (n=689)	21.3*** (n=643)
In an in-patient hospital	26.4 (n=664)	9.7*** (n=473 <sup>17</sup> )	35.9 (n=674)	28.4*** (n=517 <sup>17</sup> )
In a market by not buying food	20.9 (n=697)	14.3** (n=692)	55.1 (n=695)	47.3** (n=704)

<sup>\*\*\*</sup>  $p \le .001$ ; \*\* $p \le .01$ , Chi-square test of independence

<sup>17</sup> The n's for these variables are lower than others as we only included responses that were clearly stigmatizing and unambiguous. For example, we excluded respondents who indicated that in the case of a hospital room, they would 'self protect'.

Table 11: Cam Dong, Quang Ninh: Results of Logistic Regression of Level of Exposure to Project Activities on **Intention to Engage in Stigmatizing Behaviors** 

	Intent not to buy food from a person living with HIV (n=692)	Intent to engage in stigmatizing behavior if sitting next to a person with HIV in a food or tea shop (n=627)	Intent to engage in stigmatizing behavior if sharing an in-patient room with a person with HIV (n=473)
	AOR (CI) §	AOR (CI) §	AOR (CI) §
Activity Exposure			
To none/one activity	Ref.	Ref.	Ref.
To 2 activities	.66 (.39, 1.14)	.83 (.34, 2.03)	.50 (.22, 1.13)
To 3 activities	.27 (.14, .53)***	.63 (.25, 1.64)	.20 (.07, .54)**
To 4 activities	.19 (.08, .43)***	.08 (.01, .70)*	.08 (.02, .37)**
Constant	.79	.02**	.17

<sup>\*\*\*</sup> $p \le .001$ ; \*\* $p \le .01$ ;\*  $p \le .05$ 

Note: Logistic regression controls for age, sex, media exposure, education level, marital status, and socio-economic status (SES).

### Table 12: Cai Khe, Can Tho: Results of Logistic Regression of Level of Exposure to Project Activities on Intention to Engage in Stigmatizing Behaviors

	Intent not to buy food from a person living with HIV (n=704)	Intent to engage in stigmatizing behavior if sitting next to a person with HIV in a food or tea shop (n=643)	Intent to engage in stigmatizing behavior if sharing an in-patient room with a person with HIV (n=517)
	AOR (CI) §	AOR (CI) §	AOR (CI) §
Activity Exposure			
To no activities	Ref.	Ref.	Ref.
To 1 activity	.47 (.28, .79) **	.43 (.24, .78)**	.51 (.28, .94)*
To 2 activities	.48 (.28, .82) **	.49 (.27, .89)*	.47 (.25, .89)*
To 3 activities	.29 (.17, .51)***	.28 (.14, .55)***	.30(.15, .61)**
To 4 activities	.27 (.14, .51) ***	.28 (.13, .62)**	.35 (.16, .74)**
Constant	2.84*	.66	.96

<sup>\*\*\*</sup>p ≤.001; \*\*p≤.01;\* p≤.05

Note: Logistic regression controls for age, sex, media exposure, education level, marital status, and socio-economic status (SES).

<sup>§</sup> AOR= adjusted odds ratio and CI= confidence interval

<sup>§</sup> AOR= adjusted odds ratio and CI= confidence interval

# **Conclusions**

ddressing the stigma associated with HIV is an Aessential part of an effective HIV response. Despite recognition of the importance of stigma early in the epidemic [55], efforts to understand and respond directly to it, particularly at the general community level, remain insufficient. In response to this gap, this phase of the "Reducing HIV and AIDS-Related Stigma and Discrimination in Viet Nam" project worked with the government of Viet Nam and the communities of Cai Khe and Cam Dong to develop, support and evaluate a community-led stigma-reduction program.

Findings demonstrate that a combination of communityled activities, developed using participatory methodologies, significantly reduced stigma by shifting three specific and immediately actionable drivers of stigma: lack of awareness and understanding of stigma, fear of HIV infection through casual contact (fear-driven stigma), and values linking HIV with immoral behaviors (valuedriven stigma). This reduction is reflected in respondents' reports at endline of behavior change, both their own and observed, as well as decreased intentions to discriminate. People living with HIV and their families confirmed these observations, reporting a changing community environment that includes less stigma, particularly reductions in isolation of and increased support for people living with HIV, and increased willingness of respondents to interact with people living with HIV.

Importantly, exposure to multiple activities led to greater increases in awareness and greater reductions in fear- and value-driven stigma. In addition, the changes observed occurred in a relatively short time period (14 months), indicating that community-led stigma reduction is both feasible and practical and should be considered as a model for scaling up stigma reduction more broadly throughout Viet Nam.

While the project was successful at significantly reducing stigma in the two communities, the overall level of stigma remained high due to the very high levels of stigma at the start of the intervention. This indicates that while the project made important inroads, continued efforts are needed to sustain these changes and further reduce stigma.

Despite the encouraging evidence that fear of transmission through causal contact has been reduced in the communities, both quantitative and qualitative data show that uncertainty regarding risk of exposure to sharp instruments (e.g., from a manicure or haircut) remains among some people. This fear of contact with blood appears much stronger and deeper than fear of casual contact and will require additional efforts. Future efforts should include further development of materials that clarify HIV risk with respect to transmission of blood, particularly open wounds (scratches, cuts) and contact with sharp instruments.

Both the quantitative and qualitative data from this study show a meaningful decline in value-driven stigma at endline, with the quantitative data showing an important relationship between exposure to the intervention activities and reductions in agreement with value-related expressions of stigma. The dose effect was evident: The more project activities respondents were exposed to, the more significantly their scores dropped on the valuestigma index, with three activities being the threshold number needed in both communities to create statistically significant change. While these are important findings, the quantitative data teaches two important lessons: (1) although value-driven stigma decreased significantly by the project's endline, it remained unacceptably high; and (2) although exposure to the interventions did show an effect, the intervention dose for value-driven stigma had to be higher to bring about change compared to the dose needed for reducing fear-related stigma (casual contact) or improving awareness.

These findings reflect the challenges that the health community faces in changing deeply rooted attitudes and beliefs. The strong association between HIV and deeply disapproved of (and socially threatening) behaviors of drug use and sex work elevates this moral dimension of stigma in Vietnamese communities. An understanding of this connection therefore should serve to inform the types of interventions developed. In Viet Nam, finding ways to disassociate the disapproved behaviors of drug use and sex work from the person engaging in those behaviors is an important first step. The fact that the project had a significant impact in reducing value-driven stigma in a relatively short intervention period is encouraging. It indicates that change is possible, and the findings that emerged provide a foundation on which to work for further reductions.

# **Lessons Learned and** Recommendations

This section provides lessons learned from the intervention and recommendations on: (1) addressing the three immediately actionable drivers of stigma—building awareness of stigma, combating fears around HIV transmission, and addressing stigma derived from values—and (2) general programmatic lessons for program design and implementation.

### **Address All Three Immediately Actionable Drivers of Stigma**

Programs seeking to reduce stigma first should build recognition and understanding of it. Next, it is important to address both the fears of casual contact that drive physical forms of enacted stigma, and the value-driven beliefs that lead to blame, shame and social isolation.

### **Awareness**

Building awareness of stigma is a necessary first step for stigma reduction. Four key elements emerged for increasing awareness and understanding of HIV stigma in the intervention communities:

- (1) Create name recognition of the local term for stigma;
- (2) Expand understanding of the specific forms stigma takes in the community;
- (3) Expand understanding of the harmful effects of stigma on individuals, families and the community;
- (4) Create awareness about how stigma can influence the spread of HIV.

Increasing awareness was done in multiple ways, including through written and visual materials; having respected community members deliver fact sheets on HIV and stigma directly to households; through community meetings and participatory workshops that offered

opportunities for personal interaction with people living with HIV, when safe and appropriate; and through oneon-one interactions between community educators and community residents. In meetings and workshops, participatory learning using exercises from the *Understanding* and Challenging HIV Stigma: Toolkit for Action also were effective [34].

### **Fear-Driven Stigma**

Stigma resulting from the fear of contracting HIV through everyday contact with people living with HIV clearly has decreased in the two intervention communities. The following inputs were particularly useful in bringing about this outcome:

- (1) By acknowledging that fear of a dangerous illness is natural, program leaders reaffirmed participants' experiences and brought them into the process. Discussing the root causes of these fears and going into the specifics of what people fear in their daily lives allowed participants to reflect critically on their feelings and begin to accept alternatives.
- (2) Providing clear, specific and unambiguous information about the ways in which HIV can and cannot be transmitted is greatly appreciated by the community and helped eliminate the uncertainty and confusion that often surrounds the issue of prevention—uncertainty that clearly fuels fear-related stigma.
- (3) Providing specific information about what people can do to protect themselves, and practical steps to prevent transmission, took the guesswork out of prevention and removed additional reasons to experience fear reactions.
- (4) Giving community members an opportunity to have their questions answered by informed and trusted individuals helped to further reduce uncertainty and fear.

### **Value-Driven Stigma**

The intervention activities had a significant effect on reducing value-driven stigma, though it remained high at endline, having started from very high levels at baseline. Six lessons for future interventions emerge from this work:

- (1) The moral dimensions of HIV-related stigma link back to core values and concerns of communities, and need to be addressed explicitly and openly. Work to reduce HIV-related stigma should include workshops addressing issues of sexuality and drug addiction in general, in addition to specific exercises on HIV-related stigma. In seeking to re-orient the moral dimensions of HIV stigma, the project introduced the idea that drug addiction is a public health issue, not a moral one. Here the intervention focused on the mechanism of drug addiction to help participants understand the physiological challenges of giving up drugs.
- (2) A comprehensive fact sheet on drug addiction, harm reduction and treatment options, HIV, and stigma, should be developed and widely distributed.
- (3) It is important to disassociate disapproved behaviors such as drug use and sex work from the person engaging in those behaviors. The project found that helping community members overcome the dilemma of not wanting to stigmatize, while also not wanting to condone unapproved behavior is key. For example, drawing on the Vietnamese tradition of solidarity and providing support to people who are disadvantaged, the intervention used sayings such as "The intact leaf covers the torn one" and "When one horse gets sick, the whole stable suffers" to encourage participants to make a clear distinction between "living with HIV" and "engaging in drug use and sex work." The intervention stressed the point that regardless of anyone's past deeds, he or she is still a member of the community, and we should not drive a wedge within our own community by stigmatizing those in need.
- (4) In the Vietnamese context, further de-linking of HIV from "social evils" is important.
- (5) In the Vietnamese context, it is necessary to develop tools/skills to address institutional stigma, such as that evident in the "social evils" campaigns instituted by the state.
- (6) Changing value-driven stigma will be challenging, and change is likely to be slow, but it is possible and essential to reducing overall stigma.

### **Program Implementation**

Below are general recommendations for program design and implementation for stigma-reduction work.

Build commitment to and ownership of the stigmareduction process among community leaders to obtain *buy-in.* The involvement of trusted and respected opinion leaders, representing a range of community groups, was essential to the intervention's success. These leaders contributed to raising awareness and reducing fear within the community generally, as well as within key groups (e.g., women, youth, elderly), and were particularly influential in changing value-driven stigma. They helped to change community norms not only through implementing activities, but also by modeling non-stigmatizing behavior through interactions with people living with HIV and other stigmatized groups.

Build leaders' understanding of stigma and capacity for reducing it. To cultivate these leaders as champions for stigma reduction, it is important to build their knowledge of HIV and stigma; provide opportunities for them to address their own fears, misconceptions and attitudes; and build their capacity to reduce stigma. Depending on the particular roles implementers will take, this effort can range from a one-day participatory workshop to a two-to-five day training of trainers. In addition to leaders, all individuals involved in any aspect of implementing a stigma-reduction program must participate in at least one day of awareness building to ensure a minimal level of understanding of stigma. This will help reduce the potential for unintended stigma occurring in program activities. For example, the artists commissioned to create intervention billboards did not attend any sensitization or training workshop. Consequently, the first renderings of the billboards carried an unintended stigmatizing message simply due to their lack of awareness and understanding of stigma.

Address stigma through combined approaches. The evaluation data show that the more activities a respondent reported exposure to, the greater the increase in awareness and decrease in fear- and value-driven stigma, and the greater decline in people's intent to engage in stigmatizing behavior. Multiple activities not only reinforce each other, but also provide ongoing opportunities for people to engage on the issues, and learn and begin to change their attitudes and behavior. Respondents indicated that the ongoing nature of the intervention activities was important over the course of a year.

Strengthen people living with HIV and their support networks as a key part of a combined approach. This aspect of the intervention was particularly challenging in the project communities because few people living with HIV were open about their status at the start of the intervention. In communities where stigma is high, stigmareduction interventions may be needed first at the general community level to reduce stigma so people living with HIV feel safe enough to participate in visible programs within their own communities.

Provide written materials with detailed information *that is appropriate to the local context.* This is even more effective if combined with outreach efforts, for instance providing community members with opportunities to discuss this information with trusted and informed community leaders. In this project, respected and trained community members' hand delivered materials, which strengthened the overall stigma-reduction effect.

# Tackling HIV Stigma in Communities – It Can Be Done

HIV stigma and discrimination has been recognized in Viet Nam and globally as a crucial challenge to controlling the AIDS pandemic. Stigma undermines investments in the provision of all HIV services and stands in the way of achieving universal access to prevention, care and treatment. Reducing HIV-related stigmas at the community level is vital to creating the supportive environment necessary so that people most vulnerable to HIV are more likely to access available services.

The community-led stigma-reduction interventions reported here show that it is possible to reduce stigma in a relatively short time, and in so doing, begin to foster a more supportive environment for people living with HIV. It paves the way for further expansion of community-led stigma reduction in Viet Nam and globally by providing a simple replicable model, as well as practical stigmareduction tools (See Appendix B for a list).

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# **Appendix A: Intervention Timeline**

### The Project Implementation Timeline—Community Intervention (December, 2005 - August, 2007)

		Cam Dong ward, Quang Ninh		Month	Cai Khe ward, Can Tho	
		Baseline survey	2005	12	Baseline survey	
		Community sensitization workshop Action-planning workshop		_	Community sensitization workshop Action-planning workshop	
		Negotiation to finalize the community action plan		2	Negotiation to finalize the community action plan	
		Set up local project management unit		ω	Set up local project management unit	
		(PMU)		4	(PMU)	
		Finalize and sign the project agreement		и	Finalize and signing the project agreement	
				0		
	Sensitization meetings in cluster club meetings	Fact sheet distribution  Door-to-door visits	2006	7	Fact sheet distribution  Door-to-door visits	Sensitization meetings in cluster self-help group meetngs
	tizatic neetir	Cultural family commitment cards	06	<b>o</b>	Developed the scripts	tizatic
	n mee	developed and distributed  Developed the scripts		v	Developed and hung posters	oup n
	etings	Developed and hung posters		10	Broadcast on local speaker system  Mobile vehicle	etings
	in clu	Developed wall slogans and painted in clusters				in clu
	ıster	Mobilization for anti-stigma writing & poetry	n for anti-stigma writing &	=		ıster
		Sensitization in schools for teachers		12	Sensitization in schools for teachers	
		Mid-term evaluation		_	Mid-term evaluation	
		Sensitization in schools for students		2	Sensitization in schools for students	
				ω		
		Competition writing and poetry, drama rehearsal		4	Competition writing and poetry, drama rehearsal	
		Mobilization for drawing and writing contest in school	2007	ъ	Mobilization for drawing and writing contest in school	
		Preparation for community event		٥	Preparation for community event	
		Community Event		7		
				<b>o</b>	Community Event	
		Endline survey		9	Endline survey	

# Appendix B: Descriptions of **Key Community Intervention Activities and List of Tools**

Below are brief descriptions of the four key community stigma-reduction activities that were included in the evaluation, as they were comparable between the two communities. We also include a description of the schoolbased activities, which also were conducted in both communities, but were not included in the evaluation because they reached only a small subset of teachers and students within these communities.

### **HIV, AIDS and Stigma Fact Sheet and Household Visits**

In a previous phase of the larger project, ISDS/ICRW/ CCIC developed a fact sheet on HIV, AIDS and stigma. The fact sheet was designed to address the widespread fear of casual transmission and was distributed to the media and others involved in public AIDS education throughout Viet Nam. The fact sheet content and design were revised slightly for use in the community intervention.

### The HIV, AIDS and Stigma Fact Sheet covered:

What is HIV?

What is AIDS?

What is HIV and AIDS-related Stigma?

How is HIV Transmitted?

HIV Transmission Myths and Facts

Myths—Facts

**HIV Prevention Basics** 

HIV Prevention in the Household

The Bottom Line

Where to Go to Learn More about HIV and AIDS

Fact sheets were delivered directly to households, and also distributed during community meetings or mass organization meetings (e.g., Women's Union and Youth Union) by trusted and knowledgeable community members trained as HIV and stigma-reduction educators. The fact sheet also was distributed to teachers and members of Parent's Board of schools where stigma-reduction activities took place. In all, more than 7,500 fact sheets were distributed (4,600 in Cai Khe, 3,000 in Cam Dong).

When visiting households to distribute the fact sheet, community educators engaged households in discussions and answered questions about HIV, AIDS and stigma. Additionally in Cam Dong, educators visiting households introduced the new category of "stigma-free household" as a criterion necessary to achieve the party's "good cultural family" award.

### **Educator Training to Conduct Household Visits and Sensitization Community Meetings**

To build the community members' capacity to carry out HIV and stigma-reduction information, education and communication (IEC) activities, a group of community educators received a one-day training. Each community is organized by residential clusters (eight in total), and the action plan called for training three educators per cluster. 18 Selection criteria were agreed upon during the action-planning workshop.

### **Educator Selection Criteria**

Person who is:

- Healthy, active and enthusiastic;
- Experienced with social work in the community;
- Knowledgeable about HIV and AIDS and other social issues in the community;
- Skilled in communication and presentation;
- Known, respected and trusted by residents;
- Ready to commit to taking part in the IEC antistigma activities;
- Member of Fatherland Front, or other mass organization and social group such as the Women's or Youth Union, the Elderly Association, or Red Cross population collaborator; or head of residential cluster/units;
- Recommended by the residential cluster and the Fatherland Front.

<sup>18~</sup> In Cam Dong ward, there were approximately 2,500 households, with a population of roughly 10,000. Cai Khe ward is more than about twice as large, with approximately 4,300 households and a population

### **Training Material**

- 1. A mini toolkit with selected exercises that help to:
  - Address stigma issues: identifying stigma, understanding stigma in different settings, root causes of stigma, fear-based stigma, and shame, blame and gender stereotypes related to stigma and discrimination;
  - Improve understanding of HIV and AIDS: transmission, casual contact, prevention;
  - Move to action against stigma and discrimination and action planning.
- 2. Reading package with information on HIV and AIDS, and policy and legislation documents;
- 3. Illustration materials: pictures, figures, statistics, newspaper articles, photos, etc.;
- 4. Games, energizing tips.

Local community master trainers who attended the provincial training of trainers on stigma reduction, with technical support from the CCIC and ISDS team, conducted the training. The training focused on providing deeper knowledge of HIV, AIDS and related stigma and discrimination, and basic skills of presentation and persuasion on anti-stigma topics. Time was also spent on: introducing activities developed in the community action plan; possible IEC activities and tasks of educators; and dealing with difficult situations and possible "challenging" questions, especially related to myths around HIV and AIDS. In addition, educators received several written resources. These included the mini anti-stigma toolkit which contains a selection of easy-to-implement exercises for educators, and other IEC materials such as the fact sheet, "Basic Facts about HIV/AIDS and Stigma" and the handbook on HIV and AIDS in Viet Nam.

### **Sensitization Meetings** in Residential Units

Based on the success of the one-day community sensitization workshop held for the community leaders by ISDS/ CCIC, the community workshop participants felt all community members should get such a meeting. Hence, a key activity in the action plans in both communities was sensitization meetings, to be conducted by the community educators. The objective of the sensitization meetings was to raise awareness of the residents about HIV, AIDS and related stigma and discrimination to catalyze non-stigmatizing attitudes and behaviors toward people living with HIV and their families. In some cases, guest speakers were also invited. For example, in Cam Dong, the head of district prevention Medicine Department was asked to talk about HIV and its modes of transmission.

One day of training was not sufficient for the community educators to feel confident holding sensitization meetings on their own, so they called in the master trainers and others to help.

### **Sensitization Meeting Participation**

Cam Dong (26 meetings)

- 2,300 community residents
- 1,000 Women's Union members
- 70 farmers of the Farmer Association

Cai Khe (25 meetings)

- 1480 community residents
- 85 Youth Union members

### **School Activities**

In both communities, residents and the school teachers attended the sensitization meetings and spoke about the situation faced by children affected by HIV and AIDS. School-based interventions were added to the action plan and two primary schools, one in each ward, were selected, as well as one secondary school in Cam Dong.

School anti-stigma activities included:

- A training of trainers for selected teachers of the selected schools;
- Sensitization for teachers in targeted schools, including hands-on practice with a group of students;
- Integration of stigma-reduction sensitization for students into the classroom schedule; and
- Drawing and writing contests around stigma reduction.

### The Anti-Stigma Guide for Teachers

The guide includes eight concrete 30-minute exercises to help students:

- Understand HIV-related stigma, including forms, causes and consequences (in family and in school settings).
- What they can do to reduce stigma and discrimination related to HIV-affected children.
- Also includes a quiz of questions and answers on HIV transmission.

A two and a half day training for school teachers focused on: (1) conducting sensitization on HIV, AIDS and stigma reduction for school children; (2) adapting anti-stigma exercises from the anti-stigma toolkit in the school

context; (3) practicing selected exercises; and (4) planning sensitization and mobilization campaigns through drawing and writing competitions. An anti-stigma guide for teachers and a children's booklet were developed.

Teachers received one-day participatory sensitization training on basic information about HIV, AIDS and stigma and in how to integrate participatory exercises found in the teacher's guide into class sessions. Teachers then began incorporating the stigma-reduction exercises into their routine classroom sessions over an eight-week period. In all three schools, the sensitization process was completed for students of all grades—from grade one to grade five in primary school and from grade six to grade nine in the secondary school. In total, 1,264 students in 40 classes of the two primary schools and 572 students in 15 classes of the secondary school were sensitized with HIV-stigma reduction.

### **Children's Booklet** "For a School without Stigma"

- The content of the booklet was adapted from the fact sheet, "Basic Facts about HIV/AIDS and
- Includes: child-friendly design and appropriate language
- Basic information about HIV and AIDS, stigma and discrimination

The last school activity was a drawing and writing contest among students. Children drew pictures related to themes of "how stigma hurts," "how children are stigmatized" and "a school without stigma." Children in both schools were actively involved in the drawing and writing competitions, resulting in hundreds of anti-stigma drawings and story scripts. The secondary school conducted two competitions: a quiz on HIV and AIDS knowledge and an anti-stigma drama. One drama was performed in the ward's end-of-project community event. Prizes were given in a school contest day to the classes and individuals for the best drawings, best writing and best performances.

### **Tools**

Tools used in this project, either from a previous phase of the project or developed or adapted specifically for this phase, include:

- The Vietnamese version of: Kidd, R. and S. Clay, Understanding and Challenging HIV Stigma: Toolkit for Action. 2004, CHANGE Project/AED, ICRW: Washington, D.C.
- The "mini-toolkit," which is a selection of exercises from the anti-stigma toolkit listed above. *Toolkit* for Action: Understanding and Tackling HIV-related Stigma: Selected Exercises for the Community Trainer.
- 3. The HIV, AIDS and stigma fact sheet (slightly modified from previous project)
- The anti-stigma guide for teachers: Building a School without stigma—Teacher Guide
- The children's booklet, For a School without Stigma.

# **Appendix C: Fear and Value Driven Stigma: Items and Factor Analysis Results**

### **Factor Loadings for Fear-Based Stigma**

	Baseline		Enc	lline
Item name (questionnaire item number)	Factor 1	Factor 2	Factor 1	Factor 2
Being exposed to the saliva of a person with HIV or AIDS (208.1)	.830	061	.845	021
Being exposed to the excreta of a person with HIV or AIDS (208.2)	.767	049	.832	036
Being exposed to the sweat of a person with HIV or AIDS (208.3)	.812	079	.845	075
Sharing in-patient room with a person living with HIV (208.5)	.650	.131	.754	.076
Sharing a toilet with a person with HIV or AIDS (208.6)	.747	.095	.774	.084
Shaking hands with a person with HIV or AIDS (208.7)	.602	.004	.673	013
When going to the dentist (208.8)	.002	.796	.039	.843
When going for a haircut (208.9)	010	.734	078	.862
When going for a manicure (208.10)	.006	.829	.039	.837
Cronbach's Alpha	$\alpha = .83$	$\alpha = .83$	α = .87	$\alpha = .81$

### **Factor Loadings for Value-Driven Stigma**

	Baseline	Endline
Item name	Factor 1	Factor 1
People living with HIV are to blame for bringing HIV into our community	.742	.742
People living with HIV are promiscuous	.709	.679
People living with HIV should bear the consequences of their bad behavior	.627	.655
I would be ashamed if someone in my family was infected with HIV	.606	.503
Injecting drug users are to blame for spreading HIV in our community	.478	.683
Prostitutes are to blame for spreading HIV in our community	.474	.544
HIV/AIDS is a social evil	.434	.533
Cronbach's Alpha	α = .68	$\alpha = .73$