Our Work, Our Words:

Case Studies by NGO Health and Development Workers in Cambodia, Indonesia, Sri Lanka & the Philippines

Asian Health Institute

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3 Step Award Case Studies

Contents

Preface

Publicizing Alumni Experiences: Partnership for AHI's 4th Decade

The Asian Health Institute is a Japanese non-profit organization established in 1980. Since its establishment, it has offered learning opportunities to community health and development workers in various Asian countries. During its first ten years, AHI focused on organizing its training programs and enlarging its network with NGOs and other civil society organizations. It established mutually worthwhile partnerships with several organizations, which became counterparts collaborating in joint training programs outside Japan.

In the mid 1990s, in response to inquiries from former training participants, AHI began to explore collaboration with and among such course alumni. In 1999, a proposal from a Sri Lankan alumnus stimulated AHI to take on a new role in supporting such collaboration. This former participant wanted to apply what he had learned during AHI's International Leadership Development Course (ILDC), in particular, by setting up a participatory local governance program along the lines of one discussed by a fellow ILDC participant from the Philippines. This led to a tri-party collaboration among the Sri Lankan NGO, the Filipino NGO and AHI. This rewarding collaboration motivated AHI to re-identify its role as a facilitator in a larger context, promoting networking among community workers to provide a venue for sharing of insights and ideas based on their own experiences.

Since then, AHI has sought other forms of partnership more relevant to its former course participants. Their efforts, including both ups and downs, are the real resource AHI wants to share with a larger audience through its network. AHI's current Three Step Award project is one such approach to engender creative partnerships between former participants and to publicize their knowledge.

The first step of the project was requesting contributions to AHI's newsletter. Twelve cases from six countries were sent to AHI and appeared in the newsletters of August 2008 and January 2009. The second step was further research and hearings with the contributing organizations to enrich the content and presentation of their initial studies. These case studies form the content of this book. From these interactions, AHI has received two proposals for partnership projects, one in Sri Lanka and another in Cambodia.

Each case has its own history and strengths. We sincerely hope they will stimulate readers' further analysis and responses.

Kagumi Hayashi.
General Secretary, AHI

Introduction

This year, AHI training course participants scheduled a session on capacity building. The facilitator initiated discussion by presenting a scholarly categorization of types of capacity building. "Does your organization address these types? Or do you do something not mentioned here?" Understanding the text took some time, but gradually responses came: "Yes, we do this one," "We can't really do this one yet," and so on. After some time, Yoga, a participant from Sri Lanka spoke out: "Documentation – it's not mentioned here, but it's an important area for capacity building. Little by little, our organization supports marginalized people's ability to document things that are important to them."

This collection of stories has been elicited and published in that spirit – to support health and development workers in documenting their views. Through their wealth of experience as veteran NGO workers and managers, ILDC alumni know the perspectives of marginalized peoples as well as community development workers. Moreover, they have the capacity to analyze and represent those experiences in writing that can be understood internationally. They have a rare combination of knowledge and skills to speak out on a global level from marginalized local places.

With the spread of computers, there has been an increase in information available, and increased opportunity to publicize one's own views. But writing up a clear analysis and description takes time, effort, and some skill. It is a huge extra task for development workers busy with their urgent daily responsibilities. Through this 30th anniversary project, AHI aimed to support alumni writers in taking on this commitment. If we want our perspectives to reach the world, if we want to share our experiences in order to learn, documenting our stories is a key step.

Melisanda Berkowitz
Editor

Health Volunteers as a Means for Two-way Communication Between Community and Local Government Health System: A Case Study of Four Villages in Battambang Province, Cambodia

Kimsorn Sa, Cambodian Youth Development Center (CYDC)

Abstract

In Cambodia household expenditures on medical treatment are far higher than in neighboring countries – a heavy burden for poor families. These expenditures remain high even though public health services have become more accessible and client-friendly. This underutilization of public health services suggests a gap in communication between communities and the health system. Village health volunteer groups have been established to facilitate such communication. One stated role of these volunteers is to communicate health messages from the public health system to local residents. Another stated role is to communicate and advocate for local health needs from communities to the public health system. Given that poor people are contracting preventable diseases and paying high fees for services available more cheaply in the public system, we hypothesized that health volunteers are facing constraints to facilitating two-way communication. Therefore, to pinpoint possible constraints, this research investigated villagers' health awareness and behavior (as an indicator for achievement of community health education) and village health volunteers' activities and awareness (as an indicator for their capacities to educate villagers, advocate to health officials and participate in planning).

The research was conducted in four villages in Battambang Province, northwest Cambodia, the site of an NGO program in health education and health volunteer training. We found that villagers had gained health knowledge through the program, and volunteer organizations were active. However, household expenditures for medical treatment remain high, and problems remain in terms of villagers' water, sanitation and hygiene behaviors, under use of public health services, challenges to involving the very poor, and planning skills of volunteer organizations. To address these problems, we recommend strengthening networking and planning capacities of the village health volunteers.

1. Introduction

Overall health indicators for rural Cambodia are very poor, and the human poverty index (38.6) is comparable to Nepal (38.1) and Bhutan (38.9) (United Nations Development Programme 2007:239-40). Meanwhile, primary health care services appear to be underutilized, and household expenditure on treatment remains high. Poor villagers are paying far more than they should to treat preventable diseases. High expenditure on medical treatment has a significant impact on household quality of life. In the case study area of Moung Russey, many poor families are in debt, and more still send a family member to live far from home to gain cash income.

The causes of high expenditures on medical treatment are said to include low level of health knowledge on the part of villagers and their distrust of the public health services. Among international health sector analysts, Cambodian public health services are widely acknowledged to have improved in recent years. And yet villagers tend to avoid accessing these services.

In this context, health education and communication are a logical approach to spreading

knowledge so that villagers can prevent and access effective inexpensive treatment for common diseases. Indeed, both government and NGOs in Cambodia have been working actively on a range of health education and communication activities, including education to improve service by public health staff, television and radio communication, primary health education to villagers, and creation of village health volunteer groups and networks.

Further, national policy recognizes that the health system must identify and respond to community health needs, and assigns a role for the village health volunteers, known as Village Health Support Groups (VHSGs), in communicating those needs from villagers to the local health system, and planning to make health services respond effectively.

Thus, essential factors enabling ordinary rural Cambodians to prevent and treat common diseases appear to be in place. Relatively inexpensive treatment is available, health education is being carried out, and national policy provides a mechanism for recognizing community level health needs in the planning process.

Why then are health indicators still so poor? Somewhere, there may be gaps in communication between communities and the health system. The VHSGs appear to be a crucial link.

1.1 Research objectives

The research aimed to identify the impact of villagers' participation in primary health care and service provision, according to the following objectives:

- Assess health knowledge and behaviors of participants in KRDA's previous primary health care education
- Assess VHSG activities and capacity, particularly with regard to health advocacy and local government planning
- Analyze the main challenges for community based primary health care in Moung Russey.
- Make recommendations to government development institutions, commune councils, NGOs, local communities, and other stakeholders in community health and development.

1.2 Research site

The research for this case study was conducted in four villages in Moung Russey District, Battambang Province, included in the target area of a community based primary health care project run by a local NGO, the Khmer Rural Development Association (KRDA) from 2004-2007. KRDA's Community Based Primary Health Care project worked directly to build the capacity of Village Health Volunteer (VHV) groups through Training of Trainers in primary health education at commune level. It involved participants both from KRDA and other NGOs working on health development from 11 communes. Participants learned to conduct group discussion, educate, and raise awareness among the target population regarding disease prevention, access to health center services and referrals for hospital treatment

The four villages, two each in Korkoh and Chrey communes, included both lowland and highland sites. They were selected by the KRDA management team and key community development workers.

Like most of Cambodia, Battambang is predominantly agricultural. The province is known as an excellent rice producing region, and it is also close to the Thai border. In the research villages, the main source of income is rice production, and most families have someone engaged in wage labor. According to a previous CYDC survey of Family Household Income (FHI) in the KRDA working area, 85% of people produce and are dependent on rice seed production after harvest season. Fifteen percent (15%) of people in communes are employed as porters or government officers or own small businesses. To meet their families' basic needs, 80% of families have at least

one person migrating after the harvest season for cash employment near the border or in cities as construction laborers, garment factory workers or on large farms. The daily income estimated by community leaders is 2000 KHR to 5000 KHR per day. Local people raise pigs, chickens and cows, and plant vegetables for additional income. Estimated yearly income is 1,500,000 KHR to 3,000,000 KHR. Of the 50 villagers interviewed in the present survey, 20 reported their households cannot balance income and expenditures, that is, they are in debt.

Mothers' group and youth group members in Moung Russey discussing how to implement their health plan for the coming year.

However, in the group interviews, members of the relevant communities also indicated some increase in family capital through village bank savings, small businesses, raising animals and growing vegetables for additional income. Observation in the communities also identified an increasing number of new houses being built, increase in use of motor vehicles and equipment, and spread of TVs to most households. Material possessions are on the increase in Moung Russey, but many families are economically insecure.

1.3 Methodology

The research focused on community health participation in four major areas: community health awareness; community primary health care and networks; VHSG activities and awareness; communication and cooperation support. We collected both quantitative data (including the number of health network groups, people's participation in health education, health services accessed, and tasks performed by VHSGs) and qualitative data (on factors influencing participation in and access to health care services).

The research was carried out as action research by a team consisting of four volunteers from the Cambodian Youth Development Center (CYDC) and one KRDA staff experienced in community development work. Research team members had substantial background and experience in community development coordination, training of primary health care workers, human rights education and advocacy. The research was conducted by the five member team, from September 01 to October 25, 2008. Research methods were decided with the stakeholders directly involved with the project, including villagers, village heads, commune council members, and members of Village Health Support Group, Village Bank Committee and Village Development Committee, and relevant KRDA staff.

1.4 Sampling

Purposeful sampling was used. One hundred respondents, including 60 women and 40 men, were selected from four groups: Commune Council, Village Health Support Group (VHSG), Community leaders and NGO participants, and beneficiaries of KRDA primary health care network. Fifty villagers, 12 VHSG members and 35 community leaders were interviewed. Three respondents had no time to meet with the interviewers and were subsequently excluded from all analysis. The four groups are described briefly below.

- ✧ Commune Council: members in each commune who participated in KRDA and health center health project activities.
- ✧ VHSG: participants in primary health training with KRDA and government health centers; they are all working at village level on health support activities.
- ✧ Community and NGO Leaders: including Village Bank committee, Village Development Committee, village chiefs and NGO members working on primary health care.
- ✧ Health Network Beneficiaries: participants in health group education sessions by KRDA

2. Findings and Analysis on Primary Health Care and Development

2.1 . Family expenditure on health

The main family expenditure besides daily food is medical treatment for family members, representing more than 40% of all income. This is a burden, and sometimes pushes families to borrow money. For example, Mrs. Noung, 54 years old, who recently returned from migrant farm work at the Khmer-Thai border, reported that after her grandson returned from a two week hospital stay for typhoid disease, she was forced to borrow 50,000 KHR from a village money lender at 10% interest rate to buy medicine.

2.2 Community health awareness

Community knowledge of disease prevention and treatment is especially important for well being when people cannot afford treatment, as in the research area. Acute respiratory infection, diarrhea (due to lack of potable water and poor hygiene practice), dengue fever, malaria and some vaccine preventable diseases are common dangerous diseases in the research area. Therefore, we investigated knowledge of common diseases among the community health network members (persons who had participated in KRDA health education) and VHSG members.

Table 1 below shows the number of respondents who had participated in education sessions about specific common diseases. The diseases most widely studied were diarrhea (100%), malaria (82%), stomachache (80%) and AIDS (72%). On the other hand, fewer respondents had received education on respiratory diseases (20%), dengue (36%) and typhoid (38%). In future, health educators should consider providing more information on these diseases.

Table 1. Topics of Health Education Taken by Community Health Network and VHSG Members

Topic	No. of respondents who had participated (out of 50)	Percentage of total respondents
Diarrhea	50	100 %
AIDS	36	72.0%
Malaria	41	82.0%
Stomachache	40	80.0%
TB	33	66.0%
Typhoid	19	38.0%
Dengue	18	36.0%
Other	12	24.0%
Respiratory problems	10	20.0%

From the individual interviews and group discussions with women in the four villages, we found that 60% of respondents have received health education or had experience of child vaccinations with

health center staff in their villages. The remaining 40% indicated that they are busy working for daily subsistence, and they have no time to participate in education sessions. Most respondents said they listen to radio and TV messages about AIDS, avian flu, and malaria prevention.

Our team found that villagers in the research area have unsafe behaviors regarding water use, sanitation and hygiene. In his interview with our team, the chief of Sre O village estimated that around 20% of households used a latrine; the other families usually defecate in rice fields or very simple pit latrines. The villagers indicated about 60% of villagers use pondwater and rainwater for direct consumption. The remaining 40% boil water before consumption or use a Red Cross filter pot.

The respondents reported that they know about the risks of disease transmission from unsafe water, sanitation, and hygiene practices, but that they lack time and capital to change to safer ways. Nevertheless, some reported starting to boil water for drinking.

2.3 Mother and child health

According to national statistics, Cambodia has made good progress at reducing infant mortality, with the under 5 mortality rate falling from 95 per 1000 in year 2000 to 66 in 2005. However, although antenatal care coverage increased from 38 to 66 percent and skilled attendance at births increased from 32 to 44 percent, the maternal mortality rate increased slightly during the same period from 437 per 10,000 live births to 472 in 2005.

The eight mothers we interviewed in Kor Korh village showed a good knowledge of child vaccination services and use of maternal health services. They always bring their children to get vaccinations from health staff in their monthly visits to the village. Among the eight women interviewed, four said that they used hospital antenatal health checks and gave birth at hospital, and the other four gave birth with the help of a traditional midwife trained by professional staff. However, the group of mothers and VHSG interviewed in Kor Korh commune agreed that there are many mothers and people in their villages who still do not understand about health care and how to prevent infectious diseases properly.

2.4 Community health care choices and health networks

Health sector analysts generally agree that Cambodia's public health system has the basic infrastructure to provide effective service, but there is still a mismatch between the needs of the population and the ability of the health services to meet them. The public health system is generally under-utilized, partly because of problems in the health sector itself, and partly because of popular misconceptions about health and where to seek effective assistance for health problems.

With this national background, in our survey, we aimed to find out about the situation in Moung Roussey. Specifically, we looked at 1. Which health service providers villagers access and 2.Villagers' impressions of government health staff. We also investigated the effectiveness of youth and mothers' health networks promoted by KRDA as an approach to community health promotion.

Table 2: Health Service Accessed by Respondents in Case of Serious Disease

Service provider	No. of respon-dents (of 25)
Health Centers	37(Chrey 18, Kor Korh 19)
Private clinics	20
Pharmacy	17
Moung Russey Referral Hospital	12
Traditional healer	9
Hospital outside Battambang	8

Table 2 shows the health service our respondents accessed in case of serious disease. We found that villagers accessed Health Centers most frequently, followed by private clinics, pharmacies, and then Moung Roussey Referral Hospital. A little over one third accessed traditional healers, and just under one third had been treated at hospitals outside Battambang.

To understand why villagers still often go to private clinics for treatment instead of accessing the less expensive public health services, we asked our respondents in the four villages to give us their impressions of government health staff behavior and services. The most common response (73% of responses) was "wait a long time for treatment." For busy villagers who have to work hard for a living, this long wait seems to be a deterrent from accessing government services. While only one third of respondents reported the health staff was "careful", the same number of respondents (8 persons, 53.3%) reported "I hate them" as "I don't hate them." This may be an improvement over previous years, but many villagers still have negative impressions of the public health services.

The residents' own experiences and neighbors' experiences with health services are the basis for their evaluation. An elderly lady in Chrey II related her experience accessing services in a health center and referral hospital. She took her daughter to the health center with symptoms of dengue fever and was referred to a hospital, where she found it very complicated to get care. First she was required to pay for staying, and staff left the patient many hours before starting treatment. This slow service is said to be especially common at night and on holidays. On the other hand, a different woman reported her positive experience with government services when her child caught dengue fever. This experience encouraged her to tell other mothers in her village to pay serious attention to children's symptoms of disease and take them to appropriate health services without delay.

Health Networks Initiated by KRDA

KRDA has led a primary health care project with the cooperation of health staff, facilitating health networks of mothers and of out of school youth in each village. We attempted to assess the effects of these education group activities for promoting community health care.

The mothers' groups have formed a network of 25 members in each village, focusing on knowledge for safe pregnancy and child care. Out of school youth groups focus on reproductive health education and information about youth activities. Both mothers' and youth groups usually met every two to three months depending on the season. Although they are active and provide useful knowledge for the participants, the networks still lack effective skills for group management and strategic planning to achieve more appropriate programs. A further limitation is that most network participants are from families with medium living conditions. .Involving the very poor in primary health care education remains a challenge.

To summarize, first, village health centers were the services most frequently accessed by villagers for serious health problems. Nevertheless, many mentioned having to wait a long time for treatment. Second, the village health networks are active in educating participants, but are not necessarily able to communicate villagers' health needs to the public health staff.

2.5 VHSG role in health care

This section investigates the roles actually played by VHSGs in health care and compares it with the roles stipulated in national policy. Of five VHSGs interviewed, two were able to tell us about their role in community health participation. Mrs. Moun Toen, an active VHSG member in Kor Korh village, reported

that she represented the community in reporting information on the local health situation to the health center and NGOs, and brought back information about health, services, and projects to implement in the community. When we asked other VHSG members in Chrey II village, they seemed hesitant and unclear on their role and the scope of their work in community health. They mentioned that they have to gather people for vaccinations in their village and participated in bimonthly meetings at the health center. They work with health center staff and NGOs in implementing training sessions and poster education.

The VHSG members interviewed in both communes certified that they had passed many training courses and workshops conducted by KRDA, RACHA and government referral hospitals and that this knowledge and experience was being relayed to their communities. However, they acknowledged that they cannot understand or do all work on health projects. The VHSG members stated that they do work related to information sharing, primary health care education and promotion of IEC materials but do not provide technical or professional services.

The national policy on Primary Health Care clearly identifies the roles and responsibilities of the VHSG, along with the Health Center and the community, in promoting health care participation and creating the village health development plan. However, as mentioned above, all VHSG interviewees reported that they have never participated in designing a community health development plan or project for their village to present to any sector. The VHSG interviewees stated that they usually accept the plan or schedule for health projects from the Health Center and NGOs which have operations in their village. All 6 VHSG interviewees from Chrey commune and 6 VHSG from Kor Korh commune stressed that they do not know how to develop health project plans or how to present a strategy to other development agencies to support their community's needs.

The VHSG interviewees did not clearly understand their role in community work as prescribed in national policy, but they have commitment to collaborating with the Health Center and other development partners. The respondents noted their concern that they don't have enough time to participate in all health promotion activities because they are busy supporting their families. Lack of transportation and support allowance further limits their participation.

2.6 Communication and cooperation support

Communication about health issues has a huge impact on people's health. In Cambodia, it is especially important to communicate to villagers that health services have improved in recent years and that accessing public health care can reduce family health expenditures. It is also important for villagers to establish and popularize effective systems of mutual cooperation in times of need, as each family faces big health expenditures at some time. For this.reason, we investigated local systems of communication inside villages, between villages, and between national and local level. We found that communication and mutual cooperation is functioning to some extent, and the majority of villagers interviewed reported service at Health Centers and referral hospitals has improved.

The communication system of people in these communities is usually through small group household meetings in the evening and during traditional events and celebrations. The local population has a culture of cooperation, which is especially clear in the senior citizens' meetings and group work on common issues. Village chiefs and commune council members are supportive to health education and they participate in health promotion.

Local residents follow the national situation through TV and radio information messages. However, they still lack outside information about high

These two community leaders, and their colleagues, participate actively in KRDA's capacity building and organization building activities in Moung Russey. They are developing their abilities to elicit what local people need and to participate in planning to address those needs with the local government health system.. These two leaders are also now working as researchers with the Cambodian Youth Development Center (CYDC).

technology as well as the political environment. Further, significantly, villagers lack the regional and national level network linkages that NGOs have to communicate, share and build on their experiences.

In Cambodia, letting villagers know that public health services have improved is an important step in reducing family health costs. The VHSG has an important role to play in communicating this message. The VHSG interviewees in Chorck Touch village reported that they provide information about health center services and hospitals through monthly meetings and home visits. The Health Center staff in Kor Korh commune indicated that the number of villagers coming for health checks and consultations is increasing as villagers learn about services from NGO staff and VHSG members. Although some villagers reported negative experiences, a slight majority (6 out of 10 interviewed) reported improvement at health centers and referral hospitals, in terms of timely service and staff behavior..

3. Conclusion and Recommendations

3.1 Conclusion

The study aimed to investigate the effectiveness of primary health care education and organization building in rural Moung Russey, and to gauge the health education, advocacy and planning capacity of VHSGs, the volunteer groups linking public health services and villagers.

The target population had received some health education, but remote communities still lack knowledge about diseases and health services. They need more basic knowledge about health care and health service providers to ensure that they 1) prevent disease by changing their high risk behaviors and 2) access appropriate medical treatment without delay.

Some health networks have emerged at village level, and VHSGs are playing an important role in community health communication. However,

members still have limited health knowledge and are unclear about the scope of their responsibilities. Although national policy calls for VHSGs to collaborate in formulating village health plans, they tend to simply follow plans formulated by the government health centers and NGO partner organizations. Most VHSG members lack not only techniques for community health education and promotion, but also awareness of the national health system and policy and capacity to participate in developing community health plans. Further, small NGOs working in the area are unable to provide sufficient financial support for VHSG work and health network extension.

Although primary health care is essential for the livelihood of rural people, relevant sectors are not responding at an adequate level, and villagers are slow to change their health behaviors.

3.2 Recommendations

1. Capacity and awareness of VHSG are to enable them to work effectively. NGOs should offer frequent VHSG refresher courses on specific topics, including the roles of VHSGs.

2. VHSGs should participate more regularly in health center meetings, such as meetings to formulate community health development plans and to share health service information. Local NGOs should contact MEDiCAM and NCHP for support in providing VHSGs capacity building for community health promotion, particularly in planning and management.

3. The commune council subcommittee for primary health care should ensure participation by all relevant stakeholders, including commune council members, VHSGs, NGOs, health center staff and health network representatives, in developing and implementing health care plans.

4. Establishing village health networks including mothers' groups and youth groups is a successful strategy for community health promotion tailored to specific group needs. Group representatives should be selected for training in leadership and management and to sustain ownership.

5. Community health leaders should receive training in simple techniques for networking, such as circle information sharing, multi-case study and learning from work experiences. These techniques will help VHSG and network group members share their knowledge and contribute their perspectives to developing community health plans.

Reference

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Tackling Ethnic and Caste Discrimination in Sri Lanka: Thelingu People, Tsunami and Social Identity

Marie Princy, Janawaboda Kendraya (JK)

Abstract

In Sri Lanka's multicultural society, recovering from a 37-year war between the largely Sinhalese government and an ethnic Tamil separatist army, there is social discrimination along ethnic, religious, caste, class and gender lines. In this context, NGOs have been working to organize and empower various marginalized groups to claim equal rights and services. These marginalized groups include the Thelingu people, a semi-itinerant ethnic group or caste distinct from all the major ethnic divisions but officially classified as Tamil (Sri Lanka's second largest ethnic group). After the disastrous tsunami of December 2004, Thelingu people in Negombo faced discrimination from majority Sinhalese in shared emergency shelters, as well as bureaucratic discrimination in reestablishing residence since their previous homes were unregistered. However, many Thelingu people in Negombo were already organized in small groups supported by local NGO networks, and this gave them the consciousness and connections to use the media in accessing relief services and housing, on a par with the majority ethnic group. Through this challenging experience, the Thelingu in Negombo developed greater awareness of and pride in their caste and ethnic identity. This story provides an example of how NGO workers can support marginalized groups to fight for their rights through grassroots organizing and using media contacts.

1 Introduction

Sri Lanka is a small island nation south of India with the highest Human Development Index in South Asia. Sri Lankans belong to various diasporas, speak different languages, and follow different religions. Unfortunately, longstanding social discrimination and distrust along ethnic, religious, caste, class and gender lines divide the nation. Part of this distrust, a 37-year civil war between the largely Sinhalese government and an ethnic Tamil separatist army ended last year with the victory of the government forces. In this context, NGOs have been working to empower various marginalized, impoverished groups to claim equal rights and services, and to build inter-ethnic trust. These marginalized groups include the Thelingu people (also known as Ahikuntikas), a small ethnic group or caste distinct from all the major ethnic groups but officially classified as Tamil (Sri Lanka's second largest ethnic group).

Except for a very small population of indigenous people, Sri Lanka was populated by migration at various times by different caste and language groups from the Indian subcontinent. Nonetheless, the Sinhala majority social climate is not welcoming for ethnic minorities. Non-Sinhala ethnic groups feel they are not considered truly Sri Lankan, and the derogatory term *kallathoni*, or illegal migrant, is applied even to groups who migrated centuries ago. Historians generally agree that the ethnic group called "Sinahalese" has assimilated and incorporated various ethnic groups over the centuries. This assimilation, and pressure to hide non-Sinhalese background, continues today. It is difficult for minorities to maintain pride in their distinct identities.

Western Province, the site of this case study, is

home to Sinhalese, Tamils, Muslims and Thelingu people, and each group follows its own traditional customs. It is also the working area of Janawaboda Kendraya (JK), a Sri Lankan NGO committed to empowering the poor regardless of their ethnic identity. Established in 1981 by a group of Sri Lankan Catholic social activists, its main approach is organizing and conscientizing marginalized groups. Its objective is to enable these groups to analyze their situations and to support them in finding sustainable solutions to their problems, the foremost of which is poverty.

Poverty is common among all ethnic groups in Western Province, and JK has members from all groups. When inter-ethnic conflict occurs, JK helps the parties settle their differences amicably.

In December 2004, Sri Lanka was hit by a huge tidal wave or tsunami which changed the entire environment in coastal districts. The disaster was a huge setback for the poor, including those in Western Province. Minorities such as the Thelingu had to face a still more grievous situation, as existing social discrimination continued in day to day emergency shelter life, access to humanitarian relief, and support for reconstruction. However, because they were already organized as members of JK's local partner Negombo United People's Organization (NUPO), Thelingu groups in Western Province fought back effectively against this discrimination. They also became aware of the value of solidarity and self-respect as an ethnic group.

This case study focuses on the Thelingu community in Negombo area, Gampaha District, Western Province, and their experience after the 2004 tsunami. The first section introduces the historical and social background of the Thelingu Community in Sri Lanka. The second section introduces JK and the Negombo United People's Organization (NUPO), the two NGOs supporting the Thelingu community in Negombo. The third section reports how the Thelingu NUPO groups fought for their rights after the tsunami of 2004. Finally, the conclusion considers the lessons to be learned from this episode, and the future direction for the Thelingu of Sri Lanka.

2 Thelingu People in Sri Lanka

The Thelingu people in Sri Lanka are not clearly defined as an ethnic group in the country, and their historical background is also far from clear. However, it is clear that they are socially marginalized in a number of ways. One Thelingu from Orugodawatte expressed their social situation as follows: "If Sinhalese harass or assault us we must bend our heads to them and be submissive. But if we assault Sinhalese, the thing will be quite different. They will come with a group of police officers and torment us." The following description outlines their historical roots and present living conditions.

2.1 Historical roots in Andhra Pradesh

Thelingu language is spoken mainly in Andhra Pradesh State in India, north of Tamil Nadu. Like the vast majority of Sri Lankans, Sri Lankan Thelingu's ancestors are thought to have migrated from the Indian subcontinent. It is likely that the Thelingu migrated in waves 100 to 200 years ago, either by swimming or by boat, across the few kilometers that separate the island from the mainland. Relatively recent migrants to Sri Lanka are called by the derogatory term *kallathoni* (illegal immigrant), and this term has also been applied to the Thelingu (as well as Tamils) to suggest that they are not really citizens belonging in the country. A rough estimate suggests there are around 8000 Thelingu in Sri Lanka.

2.2 Settled groups and itinerant groups

Thelingu peoples in Sri Lanka are not homogeneous. In particular, there is a division between those who live in permanent settlements and

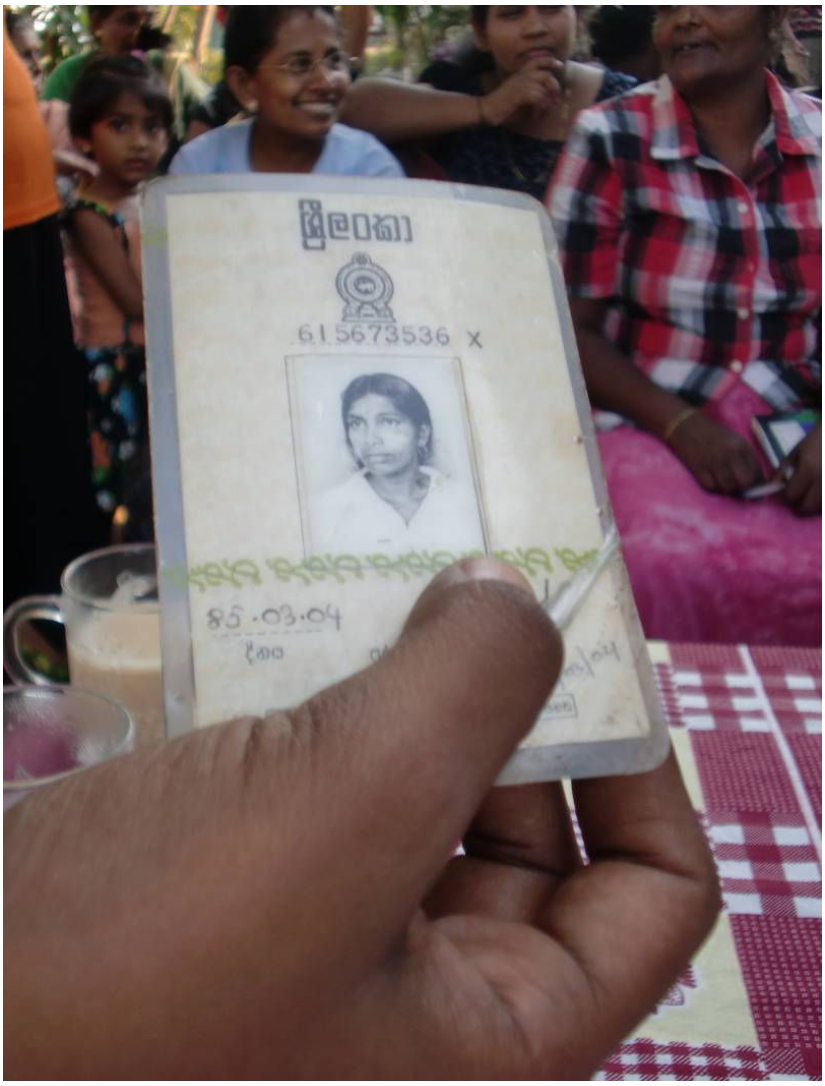
those who have an itinerant lifestyle. Many Sri Lankan Thelingu speakers are gypsies (*ahikuntikas)* with the traditional caste profession of fortune-telling and snake charming. Traditionally they move from place to place, setting up temporary shelters for a week or so and then moving on. However, some Thelingu communities have taken up permanent residence in various parts of the country, and are trying to follow the modern Sri Lankan life, buying TVs, sending their children to school, and registering to vote. There are also historical records of Thelingu caste employed by the British administration as work supervisors for the toilet cleaning caste, which suggests some Thelingu have maintained permanent residence since before Independence.

2.3 Ethnic assimilation

Thelingu language in Sri Lanka is somewhat different than that in Andhra Pradesh. Over the years, Sri Lankan Thelingu have changed their language and customs (assimilating) to follow the ethnic majority in their area, both in the Hindu Tamil north or the country and in the Buddhist Sinhala south. Thelingus with permanent settlements appear to assimilate more than traveling communities In fact, the majority Sinhalese are said to represent an ethnic mixture and cultural assimilation of many small groups. It is natural for people to alter their customs and traditions through contact with other ethnic groups. However, in Sri Lanka nowadays minority ethnic groups are threatened by hegemonic or disrespectful attitudes on the part of many Sinhalese. Like other earlier groups, the Thelingu are now in danger of losing their ethnic identity.

2.4 Caste discrimination

Although the Thelingu are assimilating to majority culture in some ways, even when they set up permanent settlements, the majority people in both Sinhalese and Tamil areas do not allow Thelingu to live in the same residential area. The Thelingu establish settlements on undesirable land outside regular residential areas. In Western Province, they are settled on the Negombo beachfront, in a garbage dump area in Kocchikade, in slum areas in Colombo



In ethnically divided Sri Lanka, Thelingus want official recognition as a distinct group. As this ID card shows, they are now registered as Tamils

(the capital), and in remote areas in Puttlam, Kurunagala and Trincomalee.

The Thelingu also face caste discrimination. Sri Lanka's government has followed a caste-blind policy since independence, and strong social welfare provision has improved the living standards of the general population, including the lower castes. However, caste-based inequality and social discrimination remains. The Thelingu peoples are viewed as one of the lower castes. They are also traditionally seen as thieves and face rough treatment from the police. For example, the Thelingu settlement in Kocchikade, close to the police station, is frequently searched by police, and when relatives come to visit they are required to register with the police even if they arrive late at night

2.5 Lack of official recognition as an ethnic group

One further challenge the Thelingu face is that they are not officially recognized as a distinct ethnic group, nor do they have a strong sense of ethnic community. When they register with the government, they are classified as Tamils because many of them have the same family names as Tamils. Given the tense relations between Sinhalese and Tamils, being identified as Tamil in a Sinhala area makes security officers and regular people distrust them. However, when they explain they are not Tamil but Thelingu, they face caste discrimination and teasing. Security officers mock them by asking to have their fortunes told. With these pressures and little awareness of the value of maintaining their own language and customs, Thelingu people are susceptible to Sinhalization.

2.6 Current social status, organization, and employment

Most Thelingu families are very poor, and some receive government support. Thelingu people living in Puttalam, Kurunagala and Gampaha districts receive aid from the government and NGOs.

Thelingu communities have built up organizations in only a few places. These include JK's working area in Gampaha district, and also in Puttlam, and Trincomalee. In Trincomalee district they have built up their own identity and have named their dwelling area Thelingu Nagar. They have been able to achieve this because of the number and density of the local Thelingu population (200 families in the district), rather than through effective organization. They are eligible to cast their votes, but they are not politically aware. They tend to stay away from party political activities, although they received voting rights about fifty years ago.

Thelingu children, especially those living in permanent residences, now participate in formal education, Most Thelingu children in settlements are enrolled in government schools and complete basic education despite social discrimination from teachers and fellow students. A few families are especially keen to achieve better living standards through education, but the number of achievers is still low. The only engineer from the Thelingu community now works abroad. There is one bank employee (with high educational attainment) in Colombo district.

Many Thelingu are involved in producing incense sticks and doing wholesale and retail sales, including itinerant trading. Women produce cosmetics, necklaces, earrings and dresses and sell from door to door. Some still practice the traditional professions of fortune telling and snake charming. Families living along the beach earn their livelihood from fishing.

2.7 Culture and customs

Thelingu culture is changing and modernizing. However, given pressure to assimilate with the majority ethnic groups and lack of ethnic awareness, they are in danger of losing their own distinct cultural heritage.

Some of the cultural changes may be seen as neutral. For example, Thelingu now register their

marriages and children's births with the government. Some Thelingu, like some other low caste groups, have also converted from Hinduism to Christianity. As for their dress, traditionally women wore long frilled skirts, long sleeved blouses and a shawl covering the upper part of the body. These clothes were decorated with colorful beads and ribbons. Nowadays many women wear Indian style sarees. Those who have money wear pearls, beads and other ornaments. Men wear sarongs and shirts. Many also wear European style trousers.

The idea that "we should protect our identity" is prevalent only among the organized community. Others consider their Thelingu identity a hindrance. Some families have given up Thelingu language and instead speak, Sinhalese, Tamil or English. School teachers instruct families to speak majority (Sinhalese and Tamil) languages even at home to help children keep up with their studies. In Sinhalese areas of the country, Sinhalese is the public language in schools, local government and hospitals. When Thelingu people speak their language in public, even when they go to clinics for treatment, they face insults and humiliation as snake charmers and fortune tellers.

JK staff asked Thelingu members, "Your language will fade away from Sri-Lanka. Don't you care? We care, they replied, but we want to avoid discrimination, and there are no Thelingu language schools. They believe that they will be able to gain social status by learning Sinhalese, and adapting to majority Sri Lankan culture. However, in discussions about ethnicity, language and human rights, Thelingu participants showed their dire thirst to win their rights and respect as an ethnic minority. They are eager to find organizations to help them end social discrimination and achieve equality as Sri Lankans.

3 JK and the Negombo United People's Organization (NUPO)

In the late 1970s, a small circle of young social activists (including the author), advised by a Catholic priest, Fr. Sarath Iddamalgoda, started organizing and educating groups of poor people in the Negombo area, Gampaha district, Western province. Their aim was to empower the poor to win their rights, and their main method was Freirean group formation and conscientization (awareness raising). In 1981, the small groups were formed into an umbrella organization named Negombo United People's Organization (NUPO). In 1982, the group of social activists formed their own organization, naming it Janawaboda Kendraya (JK), or "center for conscientization."

Throughout the 1980s, NUPO members increased as local people from various occupations and ethnic communities found it helpful in addressing local development issues. From 1989 to 1991, in a period of national political upheaval, both JK and NUPO faced a setback as both the armed groups and the government threatened the organizations' leaders, and they were forced into hiding. Since 1991, when the security situation in Western province improved somewhat, JK and NUPO have continued their work, focusing on issues identified by the members, in particular, land and housing, fisheries and marketing, and health, and they often take on local and national policies through rallies and voting.

3.1 JK, NUPO and the Thelingu people

The Thelingu community in Negombo started to get involved in NUPO in 1990. Their community consisted of about 25 families living on unauthorized land in a coastal area of Negombo Town. The houses were very simple – thatch and dirt floors. When the children got married and needed more room they would move out to build another simple house on the beach itself. Although the beach belongs to the state,

some wealthy Sinhalese families used to claim ownership and charged rent from these families.

Since they joined NUPO organization in 1990, the Thelingu community participated actively, hoping to acquire the new knowledge and attitudes required to face life in the modern world. Their children started attending the local Sinhala medium school. As members of NUPO they began to participate in united efforts to tackle problems affecting every community. Despite initial discrimination, Thelingu members were able to win their colleagues' confidence and respect, as well as develop self-confidence and leadership skills. Now, after over ten years of participation, they have the capacity to argue rationally with authorities to secure their rights.

4 Tsunami Disaster, 2004

In December 2004, Sri Lanka was hit by a huge tsunami (tidal wave) from an earthquake in the Bay of Sumatra, the largest natural disaster in Sri Lanka's history. In Sri Lanka, the damage was very widespread, affecting two thirds of the island's coastline. About 40,000 people died, 100,000 houses were damaged, and an estimated 5-800,000 people were displaced, in a country of 20 million. Damage to infrastructure and environment was estimated at over US$900 million.

During the first few weeks the common people were able to help the victims as they could afford, volunteering to shelter victims in their own houses and sharing what they had. Many donor countries, the IMF and other funding organizations participated in a seminar held in Sri Lanka in May 2005 to discuss reconstruction. A total of US$320 million, much of it in loans, was offered by Japan, the USA and the European Union to rebuild the country. Despite these funds, the government did not pay attention to rehousing poor tsunami victims. This work was left to local and international NGOs and church organizations. The government did give cash and food rations to families made homeless by the tsunami, but the support was far from sufficient, and much less than the amount given by donors. Families in Negombo area, and some members of NUPO, had to face difficult situations due to landlessness. Thelingu made homeless by the Tsunami had to face caste problems inside the shelters as discussed below.

4.1 The Thelingu community and the Tsunami

When the tsunami hit in 2004, the 23 Thelingu families who were living by the sea were severely affected. There were no tsunami deaths in Negombo, but the Thelingu were the most severely affected group in the area. The Tsunami hit at a time when they were working to improve their housing. Some families had just invested all their savings to rebuild their houses. Some families had women and men working overseas or in distant places within Sri Lanka. On the day when they were struck by Tsunami, it was from JK that they sought help, and JK promptly organized some relief activities.

However, they received shelter in a government-run emergency shelter in Vellaveediya. They were accustomed to their own traditional Thelingu lifestyle, but now they had to live in close quarters with the Sinhalese community, under whom they suffered day to day caste, ethnic, and social discrimination. Now they faced discrimination in a situation where they had to share water from the same tap and relief food from the same agencies. Although JK looked into their welfare, Thelingu families were also discriminated against in distribution of services provided by the government and other agencies.

During this time, JK asked a journalist to write in the newspaper about the plight of the Thelingu community in the shelter. The shelter residents were overwhelmingly Sinhalese Catholics, and both they and the parish priest were very upset about the article. The priest flatly denied the reports of discrimination at the shelter. He also called the Thelingu community for

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After the tsunami of 2004, over half a million Sri Lankans were displaced. In Negombo, Thelingus were the worst hit. As well as destruction of their homes, they faced discrimination in emergency shelters and in accessing aid for rehabilitation. NUPO used its media links to support their struggle against caste discrimination and for a fair share of assistance..

a meeting to inquire about their complaints. They feared that they would be expelled from the shelter and contacted JK for support.

Fortunately, the journalist also met with the parish priest, who then understood what the Thelingus had suffered. Through this experience JK also realized the urgency of educating the Sinhala community on the meaning of equality and respect.

Those who lost their homes due to the tidal wave had to face a second tidal wave in accessing support for new housing. Initially the Thelingu families faced particular difficulties accessing support because their former houses on the beach were unauthorized. The government promised to provide houses to the tsunami affected who lost their houses. However, applicants had to confirm their legal rights to lost houses. People who had been renting their homes were not eligible for housing support.

Since then the situation of the Thelingu community has changed. At the time of writing, three years since the tsunami, of the 18 families in the shelter 13 have received houses in various projects, including one project initiated by the parish priest. Others pawned or sold their jewelry to buy land and build houses, with assist-

ance from the priest. However, there were five elderly families still homeless as authorities declared they are not eligible for land and that they should live with

their children. These five families of the Thelingu community and another six families in the shelter who suffered from similar problems began to engage in an ongoing battle with the authorities to get housing support. JK helped to gain national press coverage on the issue by contacting journalists. After a long struggle the homeless families were told that they too would receive houses by July 2007.

5 Conclusion: From Crisis to Empowerment

Sri Lanka's society is divided unequally along caste, ethnic and religious lines. The Thelingu people highlighted in this case study are one minor ethnic or caste group which has suffered discrimination since their arrival from the Indian mainland hundreds of years ago. In the Negombo area, near the main city, Columbo, even after adopting a sedentary lifestyle, changing their hereditary caste occupation, and sometimes even changing their home language, they still face discrimination and police harassment. Moreover, they face the institutional discrimination of not being recognized as a distinct ethnic group, but rather being officially registered as Tamils.

The tsunami of December 2004 was a disaster for most coastal areas of Sri Lanka. In the Negombo area, the group which suffered most was the Thelingu, who had lived in unauthorized residences on the beachfront. However, this Thelingu community was able to turn their crisis into an empowering experience. When they faced caste discrimination in the emergency shelters and institutional barriers to obtaining housing aid, they contacted NGOs which had supported them for many years. Those NGOs then used their media contacts, and the story gained national press. With this outside support, the community negotiated fair treatment within the shelters and a fair share in the rehousing schemes. Through this experience, the Negombo Thelingus came to realize that although they had been rapidly assimilating to Sinhalese culture, they were still not recognized as equals. Instead of assimilating, they should maintain their own ethnic culture and work for an inclusive egalitarian society. The Negombo Thelingu community was able to grow stronger through the tsunami crisis because of its long years of organization and consciousness raising, and its external network with NGOs and the media.

Building an Inclusive Society in Indonesia: Community Based Rehabilitation (CBR) for and by Persons with Disabilities (PWDs)

Sunarman,
Community Based Rehabilitation Development and Training Center (CBR-DTC)

Abstract

As around the world, people with disabilities (PWDs) in Indonesia face physical, social and cultural barriers to participating fully in social and economic life. In contemporary Indonesia, PWDs are generally perceived as unable to become independent contributing members of society, and they also face a cultural sense of shame at being physically different from "normal" people (Komardjaja 2001). Further, government and private support services are extremely limited, especially in rural areas. However, Indonesia also has a strong movement of disability activists working to achieve human rights for PWDs as members of their own communities. Part of this movement, Community Based Rehabilitation (CBR) is an effective approach to promote disability rights and develop inclusive society in Java, Indonesia. CBR supports disabled people to become active participants in community life, and to advocate for the changes and assistance they need in order to participate.

This case study focuses on Lasini, a rural member of a self-help group (SHG) supported by the Indonesian NGO CBR Development and Training Center (CBR-DTC) in Central Java. Lasini, who cannot walk at all, now runs his own business, supports his own family, and also helps his able-bodied neighbors in the traditional system of mutual support. His enterprise challenges the negative stereotypes about PWDs and has gained him respect from the able-bodied local community. NGO strategies of forming self-help groups and networks and working with local communities are enabling disabled people to achieve more equality and inclusion in Central Java.

1 Introduction: Disability, Marginalization and Community Based Rehabilitation (CBR)

Purely medical definition of "impairment" is neither accurate nor adequate to describe the situation faced by the individual called "disabled." The extent of "ability" and "disability" depends as much on social and physical environment, and availability of adaptive technology, as on the individual's body. For example, a person with paralysis can physically move when ramps, elevators and wheelchairs are available. However, even when physical environment allows access, if cultural pressure makes unusual people feel very ashamed in public, they may avoid going out. A person with no arms, who writes with her feet, may have innate talent as a schoolteacher. But she may be refused school enrollment simply because of her impairment, or employment laws may make her ineligible to apply for a teacher's license. In turn, such social exclusion will make her economically dependent on others. Persons with impairments are often limited more by people's attitudes than by the impairment itself.

Throughout the world, people with various types of medically defined disabilities are

marginalized by cultural attitudes, social practices and exclusive physical environments. This marginalization denies disabled people their human rights to participate fully in society, as well as limiting their potential economic productivity. Given this understanding of disability, efforts to improve the quality of life of disabled people should promote social and physical environments that include rather than marginalize them. Such a social environment, where all people can easily and fully participate, is called an inclusive society.

Community Based Rehabilitation (CBR), which is based on the above assumptions, is an effective approach to promote disability rights and develop an inclusive society. This case study focuses on CBR in Java, Indonesia, where most people highly value community participation and social identity. The case study presents a success story of CBR in rural Central Java, where Lasini, a man who cannot walk, works with his neighbors and a local NGO to achieve equal respect and inclusion in his local society.

2 PWDs in Java, Indonesia

2.1 Overview of disability policy and issues in Indonesia

Indonesia has a strong disability movement, and there has been some improvement in disability policy and services for PWDs, especially since the Disability Law of 1997. According to a 2006 survey of Disabled People's Organizations (DPOs), the big problems lie in lack of policy implementation and enforcement and negligible service provision. While there are a variety of public and private services for PWDs, these are said to reach only about 10% of the disabled population. Further, services are overwhelmingly concentrated in urban areas and in institutions. The majority of PWDs, who live with their families in rural areas, have no government or NGO services. Finally, DPO leaders call for government to establish more systems for disabled people and their organizations to participate in policy development and planning (Maulani 2006).

Economic instability in Indonesia makes it hard for ordinary people, including PWDs, to maintain their livelihoods. As an indication of the overall economic situation, in 2007, the Human Poverty Index (HPI) was 18.2%, close to Sri Lanka's 17.8% (United Nations Development Programme 2007). In 1997, the country faced a financial crisis, which led to increased democracy, but also ongoing political and social upheaval. Many people's incomes have fallen sharply in the past few years.

The barriers hindering Indonesian PWDs from participating and becoming independent are illustrated by the country's low rate of disabled children enrolled in school. Indonesia has an especially large "disability deficit" (difference in school enrollment among children with disability and children without disability) according to a 2005 study of seven countries (Filmer 2005: 9-10). For children aged 6 to 11, 89% of those without disability are enrolled in school; for those with a disability the rate drops to 29%. In Indonesia, having a disability is a far greater barrier to enrolling in school than household poverty, rural residence or gender (Filmer 2005: 13). There has probably been some improvement in disabled children's enrollment rates since the Disability Law of 1996, but these statistics are not yet clear, and rapid change cannot be expected. Thus, as well as the challenge of their impairment, the majority of Indonesian PWDs face further long-term disadvantages because of barriers to attending schools.

2.2 Javanese culture and PWDs

Javanese society has many positive characteristics, but even these tend to prevent PWDs from becoming independent, contributing members of society. Disability is seen as a stigma (very negative shameful mark) rather than a normal part of human

life. PWDs are often seen as a burden and embarrassment, rather than as people who contribute to society, and they tend to internalize the view that they are second class citizens.

One cultural characteristic that tends to work against disabled people is that Javanese society is family and community oriented. Like elderly people and children, disabled people are expected to be dependent on assistance from their families and communities. As noted above, there is very little public or private welfare support for disabled people, so this care and support is generally the responsibility of the individual's family. Further, potential employers tend to think PWDs cannot be a productive and efficient human resource, so PWDs face difficulty in finding jobs.

Another characteristic of Javanese culture is that people feel a strong pressure to conform and participate "normally". PWDs often cannot hide their differences from typical peers, and they may avoid social life outside their families (Komardjaja 2001). They are viewed as "different people from another world" and segregated from others

However, as well as these cultural characteristics which encourage disabled people to be dependent and passive, Java also has some traditional practices which disabled people can use as an opportunity to participate to society, demonstrate their abilities, and thereby improve the typical image of disability. In particular, *gotong royong* (mutual community support) is a local tradition through which some disabled people can win respect by helping their neighbors.

3 Gotong Royong as an Opportunity for CBR in Java

In gotong royong, community members cooperate on a voluntary basis to identify and implement neighborhood social development projects. The tradition is still strong in rural areas, but declining in cities. The philosophy is "Many hands make light work," and all contributions are equally valued.

There are basically two types of gotong royong, namely, developing a public facility and helping a person in need. The first type usually involves building or improving local infrastructure like roads, bridges or religious buildings, and the neighborhood leader invites community members to participate. The second type is usually mutual help for traditional ceremonies such as weddings and birth celebrations, or building a house, and so on. In these cases, the person requiring help requests gotong royong and forms a volunteer committee which takes on the work.

During gotong royong, participants develop their social relations by working and chatting together. The main focus is technical issues involved in their work, but participants also take the opportunity to share other information, such as about family problems, or things they want to buy or sell. The other interest of participants is who is not attending the gotong royong, and why not. Thus, gotong royong is very important both for social development and for social communication in Javanese society.

In general, disabled people are seen as unable to contribute anything and are not expected to offer help to their neighbors. But as Lasini's case shows, some PWDs can demonstrate their abilities, gain respect from their able-bodied neighbors, and access the benefits of social inclusion by contributing services in gotong royong. In other words, Lasini's active participation in gotong royong is a good example of how marginalized people – in this case, disabled people – can make use of positive local culture and tradition gain support for a more inclusive society.

4 Lasini – Hardworking, Creative and Disabled

Lasini is around 35 years old and lives in a mountain village named Sidorejo, in Klaten District,

Lasini and his daughter (center) with fellow self-help group members in Solo. They help each other with practical issues such as savings and credit, and support each other in advocacy for disability rights. For Lasini, traveling by bus to Solo has been an opportunity to show bus crews and passengers that people with disabilities can live their own lives, and have their own income. Initially bus crews did not let him get on because they assumed he was a beggar.

near Solo City, Central Java. He has a challenging disability since both of his legs are spastic. Lasini moves on his hands, and he uses sandals on his hands. He is a member of a self-help group of disabled people organized by an NGO, CBR-DTC, in Solo. Lasini is married to Lasinem and has two daughters, 10 and 3. He has four older brothers. Lasini is the only person in his family with a disability.

Siderojo is in the foothills of Mt. Merapi, and the main source of income for local people is collecting and transporting the famous local sand and stones. This mountainous environment is challenging for a person without strong legs. But Lasini is very creative and mechanically talented. Though he has never been to a formal school, he designed and made a wooden car to improve his mobility, adapted to his own body and environment. The car has four scooter wheels connected by wooden axles and is controlled by a manually-powered stick to make it go faster and slower, a steering wheel, and a hand brake, all designed by Lasini.

Using this vehicle, Lasini works everyday to support his beloved family. His main trade is traditional bamboo basketry, and, after a six-month training in a distant city, he also produces bamboo and rattan furniture. He transports the materials on his car, and delivers the products to his customers, working about 10 hours per day.

The village leader praises Lasini:, "People feel amazed to see how Lasini lives. His family's economic status is minimum standard. But everyone has the same impression of him. He is a hard worker both for his family and for social life, to do gotong royong. Many people physically stronger and with better mobility do not contribute like Lasini does." Asked about village government's support for disabled people, he continued, "The village government is not doing much due to the limited budget. But I am willing to facilitate what I can."

Although Lasini is hardworking, creative and respected in his village, his income is very low, and many public facilities are physically inaccessible to him. His wife works as a laborer to augment the family's income, and neighbors respect their cooperative relationship as "gotong royong in the family." Still, Lasini's family cannot afford good health care, and even have difficulty buying fresh water during the dry season. In fact, a few years ago, Lasini and Lasinem lost their baby son because, like their other poor neighbors, they had no money to see a doctor, buy medicine or safe water. Further, because the public water tank was physically out of reach for Lasini, he faced an extra barrier to accessing safe water.

4.1 Lasini's education and training

Lasini is not only creative and hard working. He also has motivation and courage to initiate his own development. When he was around 20 years old, and completely illiterate, he told the teacher in a local government adult literacy program that he wanted to learn to read, write and do arithmetic. The teacher, Pak Sukano, responded by having his son help Lasini "walk" to the classroom. Lasini's success in the program inspired Pak Sukano to encourage other disabled people to join. He said, "Lasini is a disabled person who also has many abilities. He has a free mind. He is also simple and humble. He creates his own independent life. He is very intelligent. Moreover, he is optimistic, enthusiastic, positive and confident."

In the same way, through his self-help group in Solo, Lasini accessed support to attend a six-month handicraft training course with the aim of increasing his income. The training was designed for non-disabled participants, and as it was in a distant city, Lasini would have to stay in a dormitory, far away from his adapted home environment. Lasini had the courage to stay away from home and to raise awareness about disability simply by participating. He developed his own skills as a furniture maker. Furthermore, through his diligence, innovation and straightforward approach, he educated the trainer and other trainees to respect and support people with disabilities. "At first, we tended to worry and feel pity on Lasini. But Lasini did everything in his own manner. Now we do not help him unless he asks for help, like to remove a large piece of wood."

4.2 Lasini's self-help group (SHG)

Lasini belongs to a self-help group of disabled people in Solo City. The group was formed in May 2000 with the support of CBR-DTC, with the aim of supporting disabled people to develop their skills and personalities. Discussing experiences, exchanging knowledge and developing mutual respect enables them to take more control of their own lives. The group manages various activities linked to family and sexual life, economic stability of members, and public campaigns and advocacy for disability rights. Its primary activities are savings and loans for members, peer support and discussion, and advocacy on disability rights.

The SHG members also support each other by sharing each month on their recent situation, problems and successes. When Lasini's son passed away, SHG members encouraged him to rebuild his house to make a healthier living environment, help his wife cut down on smoking, and pay more attention to health care.

4.3 Using public transportation to raise awareness

At first, simply traveling to the group meetings was not easy for Lasini because of the social barriers to using public transportation, and Lasini's bus trip became an opportunity to raise awareness among the general population about the normal lives of disabled people. The cost and distance from Lasini's home to the SHG meeting site is considerable, requiring three different busses, costing IDR10,000, and taking

around 3 hours. However, the main problem was that bus crews would not stop to allow Lasini to board the busses. He would wait at the bus stop from 5 a.m., but no bus crews allowed him to board until after 8 a.m., making the trip a 6-hour ordeal.

"Maybe the bus crews think you're a beggar," suggested the group members. In Java, the common image of disabled people and public transportation is the beggars or street singers who often work in bus terminals.

When Lasini was finally allowed on a bus, the bus crews would often feel pity for him because of his disability and tell him he need not pay. The group members encouraged Lasini to keep coming by bus and insisted he should pay every time. "Let people see that we are able to work and manage ourselves," they said. Further, some of Lasini's friends and a field worker from the NGO went to the bus terminal with Lasini to talk with the bus crews. Despite the difficulties, Lasini deliberately continued taking the bus and paying full fare, raising awareness that disabled people need public transportation just like other people.

Although Lasini would have to leave the meeting earlier than other members in order to make the long journey home, he felt it was worthwhile for him to participate in the group. Asked how he felt while he travelled, Lasini said, "Tired but happy." Achieving this bus ride represented overcoming physical and social barriers to participating in society. After Lasini and CBR-DTC's discussion with the bus crews, their relations became quite friendly, and he was welcomed on the busses without discrimination. Some of the bus crew staff even ordered furniture from Lasini.

In fact, attracting attention of neighbors of the disabled people is a deliberate strategy of the self-help group, to raise awareness of disabled people's issues and to improve their social status. As part of this strategy, the SHG Solo makes home visits and holds meetings in the homes of its members. The members explained, "At the beginning, local people looked amazed to see so many disabled people having a meeting. They seem curious. At first they just look, but from the second time they welcome and smile to us and ask us questions like where we come from or why we are meeting." Thus, meeting together is an opportunity for advocacy and awareness raising among the community as well as group members.

Pak Jelan, a paraplegic peer, said of Lasini, "We feel ashamed to see how Lasini struggles, including going to Solo by bus. It is absolutely not easy. But a disabled person needs the spirit to struggle to get something in life"

Pak Jelan agrees that disabled people themselves can change people's attitudes from negative to positive through the example of a happy family, hard work, and responsible participation in social life. He often motivates people newly disabled (through injury) by pointing to Lasini as a role model.

4.4 Lasini and gotong royong

Lasini participates regularly in gotong royong, so he is well-known and integrated in the community. However, when Lasini began to participate, his neighbors were ambivalent. They welcomed him because everyone is invited to join in, including PWDs. On they other hand, they said, no one would complain if a disabled person like Lasini did not participate. According to Lasini, it took time for him to make people feel good about his involvement. Nowadays his neighbors know better what Lasini needs in order for him to play a valuable role in gotong royong.

"When people have a party using gotong royong, we ask Lasini for his help to wash the dishes," explained Pak Mitro, the coordinator of volunteers. "We make a special adapted work place for Lasini so that he can work easily. He is a responsible worker, and neighbors are very satisfied with his contribution."

Lasini made this ingenious hand-powered car, which can travel even on mountain paths. He uses it to cut and transport bamboo for his business, as well as to get about his village.

Lasini also reaped benefits of gotong royong as his house was recently rebuilt with his neighbors' help. The house is wheelchair accessible, and the walls are made of stone and sand delivered through gotong royong. One neighbor provided cement on credit, allowing Lasini to repay him little by little. People wanted to help Lasini rebuild his house, especially after the death of his baby son, because the previous house was both damp and in danger of falling down. Said Lasini, "I just prepared some food for the participants during the building work. I received some financial help from my brothers and relatives to help pay for the food."

5. NGO Support for PWDs: CBR-DTC's Patchwork Strategy of Group Formation and Multi Level Advocacy

Participating in gotong royong is a good way for disabled people to participate in society, raise awareness of disability rights, and gain respect from their neighbors, but it is not sufficient to achieve widespread change for PWDs to achieve their human rights. By offering their services, PWDs can raise local awareness that public facilities are not accessible and may stimulate communities to make improvements. However, gotong royong for public facilities requires political and financial support from higher level authorities. Furthermore, it is usually for socio-economic benefit of the community as a whole, and the community may not be prepared to take on a heavy burden for the benefit of just one or two disabled neighbors. Therefore, while gotong royong is helpful for grassroots consciousness raising, it is insufficient to achieve widespread change in accessibility of public facilities

To achieve widespread change, CBR-DTC takes a patchwork strategy, promoting the inclusion of

disability issues in mainstream programs by local GO, NGOs and People's Organizations (PO), and by advocacy to local and national policy makers. One of CBR-DTC's main roles is establishing, supporting and training SHGs to analyze their own community needs, and then to take charge of their own CBR programs in a community managed approach. However, as SHG members are often busy with survival and with local issues, the NGO secretariat (some of whom are themselves PWDs) is also directly involved in advocacy and networking at national and international levels.

One example of CBR-DTC's advocacy work is publicity about Lasini's lifestyle, and it has produced a documentary film of his life to show to a wide variety of audiences. For PWDs, Lasini is introduced as an inspiring role model. One focus of the film is Lasini's participation in gotong royong, and PWDs are encouraged to follow Lasini's example as an excellent opportunity to gain respect and to raise community awareness about PWDs' abilities and needs for support. In Lasini's own village, CBR-DTC and SHG Solo are planning two activities: 1. a Village Meeting to promote disability rights and CBR as part of mainstream local development planning; and 2. gotong royong to make the water kiosk and streets near Lasini's house more accessible for wheelchair users. In the meeting, participants will watch the documentary film and discuss Lasini's life. Villagers know about Lasini, his friends and his SHG group. Both the meeting and the road improvement gotong royong will be good opportunities for villagers to focus on community based action with concern for social inclusion of disabled people.

CBR-DTC and SHG Solo are also supporting PWDs, first by organizing new SHGs and second by strengthening existing SHGs and members. First, six PWDs from villages near to Lasini's in Klaten District are now preparing to establish a new local SHG. Discussion is underway to establish seven more SHGs in other districts. Second, to support existing groups, CBR-DTC and SHG Solo are planning to 1. run training courses, 2. facilitate multi-level advocacy by SHG members, and 3. expand the current microfinance scheme by increasing the amount of financial capital and joining a Credit Union network. Two basic types of training are planned: first, leadership, disability rights and CBR advocacy, and second, training for economic empowerment targeting both formal and informal sector work. The advocacy is carried out by SHG members split into four task separate task forces, each focusing on four different areas, namely, public policy and facilities, local government and councils, mass media, and peer support for other SHGs. Thus, the NGO and mature SHG groups are supporting practical short-term empowerment of PWDs and working towards long-term mainstreaming of disability rights as part of an inclusive society.

6. Conclusion: Human Rights of All PWDs

As Lasini's case shows, disabled people in Indonesia face cultural, social and physical barriers to participating in society. However, with some support from his NGO SHG, Lasini's positive and self-confident personality enabled him to overcome those barriers and participate in many normal social activities. Excluded from public school as a child, Lasini's strong will impressed an adult literacy teacher so much that he gained access to a class. Rejected by bus crews, he fought for access to public transportation. His ingenuity and hard work enable him to run his own business and support a family, in cooperation with his hard working wife. Further, he actively helps his neighbors in the traditional Javanese mutual support system, gotong royong, thereby gaining their respect as a productive member of society. Lasini's example has been effective in changing many people's negative stereotypes and

demonstrating that some disabled people can live as independent adults.

Nevertheless, Lasini's achievements are still unusual, and not all disabled people have Lasini's heroic personal qualities, or his abilities to be economically productive. For example, Pak Jelan, one of Lasini's SHG peers says, "I am astonished by Lasini's active participation in gotong royong. I myself don't do it. People here say it's OK. They fully understand why I don't participate. But Lasini makes an extra effort." Thus, for some PWDs, like Pak Jelan, a major attitude change is necessary to enable them to participate in grassroots advocacy through gotong royong. For other PWDs, whose impairments mean they are not economically productive, conventional participation in gotong royong is not feasible.

Little by little, disabled people and supporters must continue advocacy to make it normal for people with disabilities to go to school, take busses, work and participate in community activities to the best of their abilities. Javanese values of community and family support can be harnessed in new ways by the CBR movement so that PWDs are both free and valued, not only for their productivity or independence, but because they are human beings like other people.

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Supporting Women's Initiatives for Good Governance in Sri Lanka

Sr. Noel Christine Fernando, Sramabimani Kendraya (SK)

Abstract

Sri Lanka has a democratic government system with welfare policies and budget to support the poor, as well as a vocal media. Nevertheless, the society is stratified and divided. Poor and marginalized groups lack analytical skills and knowledge to understand their oppression or their rights. Many government officials, politicians and other powerful people take advantage of marginalized groups for their own benefit. Sramabimani Kendraya (SK) is a Sri Lankan NGO working to empower such marginalized people to act for their own rights and development. Its field area is in the villages around the Ekala industrial zone between the principal city, Colombo, and the international airport. SK uses Freirean methodology to enable people to understand and challenge these abuses, and to access welfare services as per policy. Using this methodology, SK groups have developed enough analytical ability, organizational capacity and confidence to successfully address local problems. Two cases illustrate this success. In 2006, when severe flooding linked to industrial development affected many SK members, they united in a successful campaign for flood prevention measures and maintenance by the government. In 2007, members in Delatura village challenged local government officers who had misappropriated their *samurdhi* (national government benefits to the poor). Despite harassment, the women took their demands to the police and to the central government offices in Colombo. After a long struggle, the central offices penalized the local officers for their misdeeds and fully recognized the women's financial claims.

1 Introduction: SK's Work in Gampaha District

Gampaha district, Western Province, Sri Lanka is an industrializing area, located between the main city Colombo and Katunayaka International Airport. It is home to the Ekala Industrial Zone and the Katunayaka Free Trade Zone, and it also contains many villages affected by this urbanization, industrialization, and globalization. Further, it is a multicultural area, and. offers an ideal case for examining unity in diversity. The residents have different languages, lifestyles, food habits, and religions, and yet they manage to unite .to address common issues, especially related to poverty, health care, and environmental degradation.

Gampaha district is also home to the Sri Lankan NGO Sramabimani Kendraya (SK), started by the author, a Catholic nun, in 1994, when she began organizing groups of marginalized women in villages near to the industrial zone. Subsequently various activities were started with children, youth, and students. There are nine SK women's groups in the area, including a total of around 600 women members, ranging in age from 28 to 50, and these groups are involved in a number of development activities including health care, gardening program, environmental sanitation, and support for income generating activities. SK's work has now been extended to the industrial workers in Katunayaka and Ekala, with social action and legal aid, cultural and communication activities, community health programs and empowerment of young women. All SK's activities contribute to its vision: of a society based on the universal human values of equality, justice, freedom, mutual concern, sharing and fellowship in solidarity.

This article first notes relevant development problems in Gampaha, then introduces SK's methodology, and finally recounts the stories of two successful campaigns by SK women's groups. The first case concerns lobbying for infrastructure improvement to prevent flooding worsened by the newly built expressway. The second case focuses on a successful campaign for justice by an SK women's group in the village of Delatura. These impoverished women realized that a local government official was embezzling their *samurdhi* (government financial allowance for the poor), and they had the courage and organizational strength to follow their complaint through to the highest levels. The women's achievements show the effectiveness of SK's classic Freirean methods of group formation and long term empowerment in enabling marginalized people to unite to fight for their rights.

SK's dedicated animators Kumudini Kalubowila, Fr. Sarath Iddamalgoda and Sr. Christine Fernando chat with AHI staff.

2 Key Development Problems in Gampaha: Poverty, Health, and Environment

2.1 Poverty

The majority of people in Gampaha District villages are very poor despite the modernization in the area. In fact, their economic situation appears to be deteriorating. Many families are heavily indebted, not only to the village moneylenders but also to modern finance companies which have infiltrated the villages. Roads in the marginalized areas are full of potholes, and many residents are living in low lying areas which are flooded during the rainy season. Meanwhile roads in the center of the city are better maintained and highways are constructed to serve the industrial zones. Another crucial issue is the giving away of lands by the government to investors, and this directly affects the poor as many of them are living on unauthorized lands.

2.2 Health

Low level of health among families is a major issue to which these communities are now gradually awakening. Malnourishment is still common. They are living in unhealthy conditions due to inadequate sanitary facilities, water supply and shelter. Further, as government services are insufficient, many unlicensed medical practitioners operate in the area, exploiting the poor.

2.3 Environment

There has been a remarkable increase in environmental pollution during the last decade destroying natural ecosystems, depleting resources, and weakening traditional knowledge. As a result of this destruction, people are being displaced from agriculture-related livelihood. Thus environmental pollution directly damages the health of residents and also exacerbates poverty in the area.

3. SK's Methods: Freirean Empowerment

SK's methods follow the Brazilian educator Paulo Freire. Its vision is development for all through

a process of empowerment of the poor, transformation of relationships within the community, and improvement of living conditions to allow human dignity. Its mission is education for freedom at the grassroots level. SK mainly works with women and children, vulnerable members of the Gampaha society. Its methodology is to encourage local residents to form small self help groups for subsequent peer learning and action. SK brings the poor together because its aim is neither welfare nor support for individuals. When an individual approaches SK workers with a problem, s/he is asked whether s/he knows other people affected by the same problem. Usually the answer is yes. The individual is then motivated to look for such people and bring them for group meetings to address the issue.

The animator, or NGO group facilitator, must be skilled at drawing out intercultural communication between group members, who often hail from different ethnic and religious communities. The animator initiates group analysis to identify causes of their problems, challenging members to answer questions, and utilizing stories and exercises as appropriate. If the group members say their problem is being poor, the animator may ask questions such as, why are your poor? How did you become poor? When and where? Who is affected? It can take a long time for new group members to learn to think and discuss together. After causes are identified, possible solutions can be considered.

The critical understanding gained through the analysis will lead to the next task: deciding on action to address the causes of the problem. In order to get maximum participation and solidarity, it is very important that the group comes to a consensus about the course of action. Over the years, many groups followed this process of action, reflection and further action (praxis), and successfully solved key problems in their communities, gradually building up the group member's capacities and confidence.

Soon the participants also realize that as a little group, they cannot have any impact on pervasive injustice in the social system, but if several groups join together they can have a positive impact. Therefore, networking among the poor at the district and the national level is important and remains a long term challenge for SK. Below we turn to two cases where SK groups analyzed the causes of problems affecting them, took initiatives to address these causes, and, despite intimidation by more powerful people, achieved significant changes that improved their lives in a practical way and also testified to their political empowerment.

4. Case Studies: Infrastructure Development and Welfare Corruption

4.1 Lobbying for flood prevention infrastructure

In 2006, the impact of floods was more severe than in previous years. Families from a number of villages had to seek shelter in schools and at the SK centre. But while emergency relief was proceeding, a group of women began to talk about the causes of the floods. We agreed upon a date for a community meeting to discuss this matter at length. The meetings led to a campaign to lobby local and national politicians and government offices to improve and maintain infrastructure preventing floods.

At the first group meeting, participants found that unlike before, in recent years the rain water stagnated and did not pass through drainage canals into the sea. The SK animator began posing questions to stimulate analysis: What really made floods so severe? Was there an increase in the rainfall? Why didn't floods subside? Two most important causes were identified. One is that the authorities had neglected their responsibility to maintain irrigation canals. The other was that the half built express highway was acting as a dam.

SK women's group leaders from Gampaha district met with AHI visitors to discuss their successful group actions. The leaders' active campaigning pressured the local government to prevent flooding in the area. A separate campaign won welfare recipients their rights against corrupt local officials.

The animator continued her questions: Was it the first time that the area was flooded? Why was it that no action taken earlier? A discussion then followed as to why the officials had neglected their responsibilities for so many years. The group concluded that officials and politicians are not concerned about the issues affecting ordinary people, but rather get involved only in activities which bring them personal advantage. Another factor was the poor's weak organization and inability to hold the authorities accountable.

Then discussion switched to the express highway: For whose use it is constructed? How is it creating problems for the community? What could be done to improve the situation? The participants realized that the road was not meant for the poor but for wealthier Sri Lankans and foreign investors to travel between Colombo and the international airport. Unfortunately, it has been constructed without regard for its impact on the environment and people living around. When the participants realized this, they designed a plan of action to reduce future flooding. Meanwhile, the animator posed more questions to clarify how their own actions and inactions ("internal causes") had also contributed to the flooding. That is, they were often apathetic, they underrated their own capacity to bring about change, and they had only a weak sense of civic responsibility.

The groups identified two measures to improve flood prevention infrastructure. First was the cutting of a canal across the express highway. The second was the clearing of all neglected irrigation canals. Both measures required support and action from local and central authorities. Their previous experiences taught them that they themselves must take action to make change. Group members volunteered to collect necessary data and scientific analysis of the flooding. Another few wrote a petition explaining their demands, others lobbied local government officers and

politicians, while still others sought the support of local opinion leaders. Thus, everyone worked for the common cause.

The petitions were sent to all responsible local authorities. When there was no response, members went to meet the officials in their offices. It was the first time ever that they as a group had met the government authorities on a common issue. Group leaders met the district secretary and explained the situation, and were introduced to the emergency services officer, who finally agreed to visit the affected areas.

Achieving a hearing with the elected Member of Parliament (MP) was one of the most challenging steps in the campaign. The MP's staff tried to deter the women. "They did not welcome us at the office. It was very hesitantly that they gave us an appointment to meet him. But when we went there on time we were once again told that he had gone abroad, and on another occasion that he was in Colombo." Thus often the community leaders had to wait for hours to meet him. When they finally met him he approved their demands, but nothing was carried out. So again they went to meet him, waiting for hours. Nevertheless, as the members narrated "Finally the MP realized that we cannot be deterred. He too has realized that we are now organized and empowered and politically alert. In fact, once he asked, 'Where did you learn your strategy?'"

Even after funds for canal clearance were approved, the members had to keep watch to ensure proper work because public works are done on contracts given to private individuals in some way connected to the politicians. Members learned to be vigilant and constantly check whether the work was being done according to the set standards and funds allocated for the project were utilized properly.

Thus, after a long struggle, the group members were successful in getting the relevant authorities to carry out both of their proposed flood prevention measures. One of their learnings was about politics and social hierarchy. At one meeting leaders noted, "When these activities were organized, the local politicians began to create trouble for us because we were doing these things by ourselves. In fact we got things done which they could not do for years. One of them yelled at us for going to see the MP without his knowledge." Gradually people began to realize that even issues such as flooding and environmental protection are directly related to social structure and politics.

4.2 Campaigning against embezzling of Samurdhi welfare funds

Samurdhi is the financial support provided by the government to the poorest families. There is an officer in every village to facilitate the samurdhi services provided by the government. The samurdhi campaign in Delatura was sparked off in 2007, when SK members and recipients faced harassment by local officers for refusing their demand for bribes. The SK members realized that the harassment was unjust and, based on their previous actions, knew how to campaign for justice. Nevertheless, the campaign was a tremendous challenge for these poor women, and their success testifies to the capacity and solidarity they have developed through SK's animation.

The harassment began when officers questioned SK members Janaki and Rita about non repayment of their loans. In fact, both women had stopped repayment since the officer had not given back their pass books. The two suspected their repayments had not gone to their accounts but into private pockets. The women first reported these irregularities to the local manager. But to their surprise, he sided with the officer. When Janaki and Rita refused to repay the next installment, the samurdhi officers threatened them both with legal action. Subsequently, Janaki and Rita's samurdhi benefits were cancelled and they were summoned to the police station.

Children of SK members welcomed AHI staff to Gampaha with flowers and dance.

At this stage, naturally both got frightened. However, the SK group leaders then called a committee meeting and discussed the matter in the presence of the SK animators. They arrived at the consensus that this matter affected the whole community. As such, the group decided that they should accompany Rita and Janaki to the police. During the inquiry, the group explained the matter to the police officers. Convinced by the women's testimony, the police officer advised the samurdhhi officer to return the women's pass books. The group came out of the inquiry with a lot of self confidence.

The leaders then reflected on the whole episode and decided to go to the local samurdhi office to ask for their pass books. Again, however, they faced a strong reaction from the samurdhi officers. Finally they were physically chased out of the office. It was a moment of defeat. But, after a meeting at the SK office they realized it was not a reason to give up the struggle. After all, they had the support of the police. Their next steps were to inform the police and then take up the matter with the Director General of samurdhi in Colombo. As correspondence was slow, SK organized a vehicle for the women leaders to go to Colombo in person.

After returning from the Samurdhi Head Office, the women reported, "Our plan was to meet the Samurdhi Commissionner General. At the reception we were told that he was not available. Then we asked for the deputy. He too was not available. But we did not get discouraged. We paused for a while. Then one among us suggested that we show the copy of the letter we wrote and asked that we want to meet the most senior officer available. Thereafter we were directed to meet the Samurdhi Accountant. We sat with her and discussed the matter for a long time. Finally, she agreed to send a team for an inquiry."

The women were not only jubilant, but rightly proud of their struggle. Within a week, as promised, a team came to the village and met the victims in their homes, to collect first hand information regarding the incident. Other community members also revived their hope of achieving justice.

Unfortunately, though, the Delatura samurdhi officers did not stop their campaign against the women leaders and SK. These government officers used their political influence to undermine the unity among the SK women groups. They spread wild rumors that SK was misleading the villagers, had a hidden agenda and that SK was supporting the Tamil Tigers (the army fighting a civil war for an independent country in the north of Sri Lanka). In some instances the officers damaged the organization. A number of members withdrew their links with SK. This is quite natural as the country was under emergency law, and any activity for justice for the poor could be interpreted as anti government terrorism.

Family conflicts also hampered the women's activities, and in some cases the women's development as leaders had a direct impact on family relationships. While some husbands encouraged their wives to play active roles, accompanying their wives to meetings and coming to take them home by bicycle, many were against their wives' involvement. In a real blow to the network, Janaki, one of the two campaign initiators, had to withdraw completely due to a family conflict. Some husbands felt jealous when their wives played a prominent role in the village. Some husbands had party allegiances and did not let their wives criticize their party or its leaders.

Further, as poor women busy with their everyday responsibilities, participating in the campaign was physically demanding. When they took part in any activities, especially away from the village, they had to prepare their family's meals before they start the day and return before the children get home from school. Many women brought their children to the meetings. Naturally, there were times when the children cried and disturbed everyone and the mother found it difficult to concentrate on the proceedings. But the women went on.

Finally this year, samurdhi beneficiaries have being fortunate to see the positive results of their long struggle for justice. After the leaders' repeated visits to the head office, hundreds of pass books were returned to their owners. The monies that had not been properly accounted for were finally credited to their accounts. The officer concerned was transferred from Delatura, and the amount he misappropriated is to be deducted from his monthly salary.

5. Conclusion: Adapting Freirean Methodology in the Global Era

In both the campaigns introduced above, the leaders showed tremendous courage, tenacity, vigilance and sense of justice. They gradually developed confidence and know-how through experiences such as regular group meetings and smaller scale campaigns. SK's Freirean Action-Reflection Praxis methodology served as the basic tool for ongoing empowerment of both the Sramabimani Team and the Sramabimani People's Movement. As noted above, particularly given Gampaha's involvement in the global economy, a remaining challenge for SK and its members is to expand their solidarity networks to address global-local issues at national and international levels.

Improving the Community Based Management Information System (CBMIS) for Reproductive Health in Camiguin, Philippines

Raymundo C. Agaton Jr.,
Philippine Rural Reconstruction Movement (PRRM)

Abstract

An accurate system for collecting, managing and sharing relevant information is essential to promote reproductive health, partly because it helps focus attention on data rather than ideology in this controversial field. If properly implemented, a Community-Based Management Information System (CBMIS), where data is gathered at household level by community members, is potentially more accurate and inclusive than data gathered by local health facilities. Therefore, a CBMIS is a promising management information tool for local government units, health practitioners and civil society organizations to come up with timely and effective decisions.

In the Philippines as elsewhere, reproductive health is highly controversial, and also vitally important for people to achieve sustainable development. Further, since devolution of health services, central government policy to allow couples access to family planning is often derailed by local politics. This case study focuses on health management information systems in Camiguin, a small island province at the northern tip of Mindanao in the southern Philippines, and argues for the strengthening of the provincial CBMIS to promote reproductive health. The argument has two main sections. First, fieldwork at the provincial and local health units indicates that the current system of information collection and use is inadequate to provide accurate information or ensure that relevant stakeholders are involved in decision making. Second, the experience of a national NGO, PRRM, in establishing a basic CBMIS for its health programs in Camiguin, suggests that such a system could facilitate better reproductive health in the province. Further, PRRM's experience indicates that building capacity of local level health workers to collect data and participate in decision making is critical to making a CBMIS effective.

1 Introduction

Accurate information is essential to create and implement health programs responsive to people's needs. Accurate information is particularly important where there are limited funds, controversial issues, and lack of political will to provide services, because such information clarifies people's needs and allows stakeholders to identify rational and efficient health program options.

Accurate information is also important in promoting reproductive health (RH), a critical field in healthcare as it directly concerns the most vulnerable sector of society – women and children. Moreover, reproductive health is a controversial issue in many countries, including the Philippines. In the Philippines, attitudes to reproductive health and family planning (FP) are ambivalent, and national policy implementation is often weakened by lack of local government support. In this largely Catholic country, the Church is against artificial contraception, while the Philippine government recognizes the importance of giving couples control over their family size. The Department of Health aims to promote reproductive health through a two pronged strategy of providing health services to pregnant women (safe motherhood)

The writer, Dondon (right) and his colleague, Pin. Pin is an AHI alumna from 1984, when she was working in Negros. Later she joined PRRM in Camiguin, where she worked in the health project more than 10 years.

and family planning services to couples. Meanwhile, devolution has given local governments authority to set their own budget priorities for services including health, and this tends to derail national reproductive health policy. In this context, an effective system of data collection and information dissemination is crucial to support the government's efforts to identify and respond to people's reproductive health needs.

However, conventional health information systems in the Philippines have generated low quality data, and this has weakened responses by local governments. This is especially true for data about women who wish to avoid further childbearing or postpone their next child but who are not using any method of contraception, known as *unmet family planning needs*, i.e., the gap between some women's reproductive intentions and their contraceptive behavior. This gap poses a challenge to family planning programs: to reach and serve the millions of women and men whose reproductive attitudes resemble those of contraceptive users but who, for some reason, are not using contraception.[1] Accurate data is needed to understand and respond especially to the concerns of women with unmet needs, and to inform policies and programs that can more effectively support reproductive health.

Since the late 1990s, Community Based Management Information Systems (CBMIS) have been actively promoted by the Philippine Department of Health to gather quality data as a basis to respond effectively to community health needs, particularly in reproductive health. Experiences of many provinces, beginning with the province of Pangasinan province in the north and Iloilo City in the south, have already demonstrated that CBMIS can be useful in identifying and referring clients in need of family planning, immunization and vitamin A supplementation (Management Sciences for Health [MSH] 2001:1).

This case study includes an analysis of the current health information management system in Camiguin, a poor island province in Northern Mindanao, and also draws on the experience of the NGO PRRM using basic CBMIS tools in implementing community based reproductive and

[1] The Philippine Family Planning Program component of the UN Population Fund (UNFPA) on the other hand defines the demand for a family planning (FP) as the desire of couples to space or limit their children, and reduce the risks of pregnancy and childbirth.

general health programs in Camiguin. Finally, the study recommends strengthening of Camiguin's CBMIS to better address unmet FP needs, and as a basis for establishing provincial level population policy.

2 What Is a CBMIS?

The Community-Based Management Information System (CBMIS) is a monitoring tool promoted by the Philippine Department of Health (DOH) and mandated as a health intervention program and an important tool for the improvement of the health and welfare of mothers, children and other members of the family. A defining element of the CBMIS is some level of participation in information gathering and/or use by community health volunteers, known in the Philippines as Barangay (village) (BHW). Ideally, each BHW is assigned a number of households to survey, and submits the completed survey tables to the local level health official, the rural health midwife (RHM) (MSH 2001: 3). As mandated by the DOH's reproductive health program, CBMIS also provides information and services for couples of reproductive age to plan their childbearing through legally and medically acceptable methods. The CBMIS gives service providers accurate information on potential FP clients and users in need of FP services. In particular, it helps service providers understand what method is preferred or used by the clients and potential clients. It also provides FP information, education and services whenever and wherever these are needed. This aims to help couples and individuals achieve their desired family size within the context of responsible parenthood,[2] and improve their reproductive health. The Management Sciences for Health, an NPO research unit working closely with the DOH, identified four steps to a CBMIS: "identifying women and children who need services, summarizing and analyzing family profiles, planning and implementing service delivery interventions, and maintaining the CBMIS" (MSH 2001:3).

[2] The concept of Responsible Parenting, as promoted by the Philippine government, refers to the proper upbrining and education of productive and civic-minded citizens.

3 Situational Analysis

3.1 Camiguin profile

Camiguin is a poor island province located off the northern part of mainland Mindanao, and home to active volcanos. It is the second smallest province in the Philippines and has a population of 74,232 (National Statistics Office [NSO] 2002). Population growth rate in the 2000 census was 1.38%, far below the national rate of 2.36% (NSO 2002), and a population density of 3.45, and the population is relatively young. The economy of the province is predominantly agricultural, with an incipient tourism industry. The dependence on agriculture and fishing in a province with cultural productivity, dwindling natural resources and practically no value-adding activities, is one of the major factors behind the estimated poverty incidence of 42% in 2006, near average for Region X, but far higher than the national average of 32.9% (National Statistical Coordination Board).

3.2 Provincial health profile

Camiguin has four main health stations, five health centers, 20 nutrition centers and 14 barangay health centers. The number of rural and barangay health centers is already in accordance with the prescribed ration of one for every 20,000 residents. Following this ration, only two more barangay health centers need to be established, while the number of Rural Health Centers can merely be maintained. However, to make them accessible, the province needs many more barangay health centers as there are few roads on the island. Further, as Camiguin's island

location limits access to the Mindanao mainland, existing government health facilities need to be rehabilitated and upgraded.

Reproductive health in the province is a mixed picture, and statistics from different sources vary. Generally in the Philippines, the wealthier provinces and families show a far higher Contraceptive Prevalence Rate (CPR), particularly of modern methods and lower fertility rate (Philippine Institute for Development Studies: 1). However, the CPR in Camiguin was 45.9% in 2003 (Commission on Population), not far from the 2005 national average of 49.3%.

In terms of MMR, as Camiguin's total population is less than 100,000, just one maternal death in a year makes a large difference in statistical terms. In 2003, there were no maternal deaths in Camiguin as in most of the provinces in Region 10, while the national average was 137.7 per 100,000 births in 2004, representing a slow long-term improvement (Asian Development Bank [ADB]:76-77). Access to maternal care in Camiguin is average for rural areas.

At the national level, infant and child mortality rates have steadily decreased over the past two decades, and IMR was estimated at 29 per 1000 in 2003 (ADB 2005:76). However, there appear to be wide gaps in IMR between richer and poorer sections of the population and among geographical areas.

This complicated statistical picture again indicates the need for more relevant information to pinpoint the local barriers to reproductive health, particularly for the poor.

4 Objectives and Methodology of the Study

The study investigated strengths and weaknesses of the current management information system for family planning under the decentralized government system in the province. Study data was derived from recent report documents of the Provincial Health Office and results of interviews and focus group discussions with key informants and health personnel in the province. The study covers the five municipalities in the province.

4.1 Health management information system in Camiguin

Below are descriptions and analysis of how the Provincial Health Office (PHO) in partnership with the local government units generates data and manages health information. Figure 1 depicts the system in diagram form.

Data Generation and Reporting

Data gathering starts from the Barangay Health Workers under the Rural Health Midwife (RHM), assigned to their respective catchment areas (or cluster of barangays). Each RHM maintains a Target Client List (TCL), provided by the Department of Health (DOH), in which all barangay level information is recorded. TCL contains client data about pre-natal care, post partum care, and expanded program of immunization, TB symptomatics, food and micro-nutrients supplementation, and new cases of acute respiratory infection. Based on TCL, the RHM prepares a monthly report, which is submitted to the Public Health Nurse (PHN). The PHN collects the RHM reports and consolidates these into monthly reports at the Rural Health Unit (RHU) of the municipality. The reports are then consolidated on a quarterly basis. The DOH's Field Health Services Information System (FHSIS) quarterly form is accomplished and submitted to the Provincial Health Office (PHO). The PHO is supported by the Provincial Health Team (PHT), the extension office of the Regional Health Office (RHO).

The primary function of the PHT is to provide technical assistance as well as monitor the different

health programs of the Local Government Units (LGUs). The PHT also comes up with its own reporting system complementary to the PHO. However, key informants observed that reports are seldom accompanied with quantitative analysis of the data presented. Further, since devolution, the PHO no longer exercises direct control and authority over the local health centers or RHUs. The information generated at the municipal level is limited only to the health concerns of the municipality on defined plan and programs.

Data Utilization

The purpose of generating data is to use it in planning based on the situation and needs it portrays. However, data generated through the existing health MIS has not been effectively used by local governments as a basis for planning and management. This is because local chief executives tend to use their discretion to approve programs and budget allocations based on their own priorities rather than on the needs of the community as indicated in the data gathered. This often results in low prioritization of health, and reproductive health in particular.

Feedback System

A properly designed MIS must have a well-defined and efficient channel of information dissemination and feedback systems. In the current set up, the PHO hands down the FEIS forms to the public health nurse at the RHU (municipal level) who is often left to generate data without sufficient follow-up and supervision. The PHO collects the forms for tabulation and analysis, but does not validate the data. Feedback then is limited to providing important information, and the public health nurses are not involved in making decisions. Trainings and capacity building are also carried out at the regional level, and municipal level workers have fewer opportunities to improve their skills.

4.2 Key findings from interviews

Limitations in designing and assessing management information system

In the case of the Provincial and Municipal Health Office, there is a lack of procedures to ensure the accuracy of data generated. Most of the staff employed to gather data are not adequately trained in data collection, let alone tabulation, analysis and interpretation. Further, there is no computerized system for tabulating, analyzing and reporting data so that it is easily accessible to health workers and policy makers.

In analyzing data, there were various conspicuous gaps in the MIS, as follows:

- No review of types of data collected, to consider information not currently provided (see 4.2.2)
- Lack of awareness regarding frequent and systematic data collection
- Methods of collecting information depend on availability of funds. When no funds are allocated, no data is collected
- Gaps in analysis and interpretation of data。

Insufficient information on factors affecting access by the poor

It appears that the very poor in Camiguin have limited access to reproductive health information. Given high levels of poverty, strategies to ensure these people's access to RH services and supplies are of great concern. However, the current information system provides little information on factors affecting access by the poor. Data is insufficiently disaggregated to accurately depict and address the inequality of access.

Delays in information flow hinder decision making and program monitoring & evaluation

The existing bottom-up reporting and planning system from village to district is interrupted by delays

in reporting and feedback. The system is improving, but too slowly.

Under devolution of health services, political will on the part of local government strongly influences how the FP program is managed

Local leaders' perceptions of the importance of FP towards sustainable development determine the supports provided for FP program implementation. Only few local governments of the study area provided local budget for contraceptives and were highly dependent on supplies provided by the Regional Health Office.

Discrepancy between demand and supply for certain types of contraceptives

Due to lack of monitoring and inadequate reporting system, current provision of contraceptive types frequently fails to meet user needs. Further, information on FP contraceptives, including their side effects, is not always adequately provided at the service delivery point.

4.3 Summary of findings

The above findings indicate that while an MIS is in place in Camiguin, it has serious shortcomings in terms of the type of information collected, accuracy of information, and use of information to respond effectively to current client needs. In terms of the four steps of CBMIS identified by the MSH – identifying potential clients, analyzing family profiles, planning and implementing services, and maintaining the CBMIS – Camiguin's system is weak in all areas, but particularly with regard to step 4, monitoring and maintaining the CBMIS. There are clearly insufficient indicators on factors affecting FP access by the poor, but there is no regular review or assessment to improve the system.

5 PRRM's Initiatives with CBMIS in Camiguin

5.1 Background: PRRM in Camiguin

PRRM's field programs span 22 provinces throughout the country, and its "sustainable area development" model is being implemented and refined in more than 600 communities, in partnership with organizations of farmers, women, and the youth. PRRM advocates and campaigns for policy reforms in its pursuit of just and sustainable rural communities. It is one of the oldest non-government organizations in the Philippines providing community health services through Community Health Workers (CHWs). Of particular relevance is PRRM's experience promoting sustainable community based health through organizing and supporting active involvement of community volunteers.

PRRM's first project in Camiguin was the Responsible Parenthood and Family Planning Program, which ran from 1991 to 1993. This program was expanded and integrated within PRRM's subsequent Sustainable Island Development Program (SIDP). PRRM's key strategy has been to strengthen civil society through building the capabilities of community organizations to respond to local challenges and eventually take responsibility for their own area development.

There are two primary components in this process. The first is encouraging the formation of Barangay Health Committees (BHC). The BHC is a vehicle for identifying health needs and responding to them by direct community- based services, by linking up with external non-government networks or "pulling in" government services. The second involves training community health workers, who also serve as BHC members, and promoting effective indigenous health practices.

Cooperating with provincial and rural health units, PRRM undertakes the following health-related

Pin with some of the PRRM Community Health Workers (CHWs) whom she trained. Some CHWs are now active as Barangay Health Workers (BHWs) employed by the local government. According to Pin, CHWs have both excellent skills and strong commitment to their communities, and they could still contribute more to the health system.

activities at the community level: a) research and documentation (community diagnosis, community health planning); b) health organizing (forming Barangay Health Committees); c) capability building of community health workers (CHWs) to undertake health service delivery; d) provision of basic health services (with medical service kits); and e) networking and linkaging.

PRRM's village level health activities in Camiguin have succeeded in establishing sustainable, integrated health services, by organizing residents and linking up with local government and NGO finance. One major achievement has been gaining local government budget support for the CHWs organized by PRRM. When the PRRM health program started, the CHWs were purely volunteers with no financial compensation. After realizing their heavy workload, PRRM successfully lobbied the local government units to subsidize their allowance and incentives. Some CHWs have also been employed by the local government as Barangay Health Workers (BHW).

Another major achievement has been villagers' establishment and operation of small pharmacies, supported by PRRM micro-financing schemes for health. These pharmacies have brought sustainable health services closer to the people. Thus, PRRM's interventions have helped villagers achieve better healthcare by linking up with local government and participating in running community health services.

5.2 PRRM's data boards: simple and effective CBMIS tools

One of the health activities undertaken by the Community Health Workers in association with the local government has been establishing and gathering important health related information in data boards, a rudimentary CBMIS. These data boards have been installed to monitor PRRM's health program implementation, gather essential data and disseminate information for health. The CHWs are familiar with their own communities, and they are carefully trained and supervised in data gathering techniques. The accurate information they gather is then seriously considered by the Barangay Health Committees, in which they participate, in making decisions regarding subsequent health activities. Using data boards has enabled Barangay Health Committees to pinpoint health achievements and needs and facilitated planning further appropriate interventions. Further, the information gathered, along with community health workers' insight into their own communities, is shared with the local government health staff. The data is

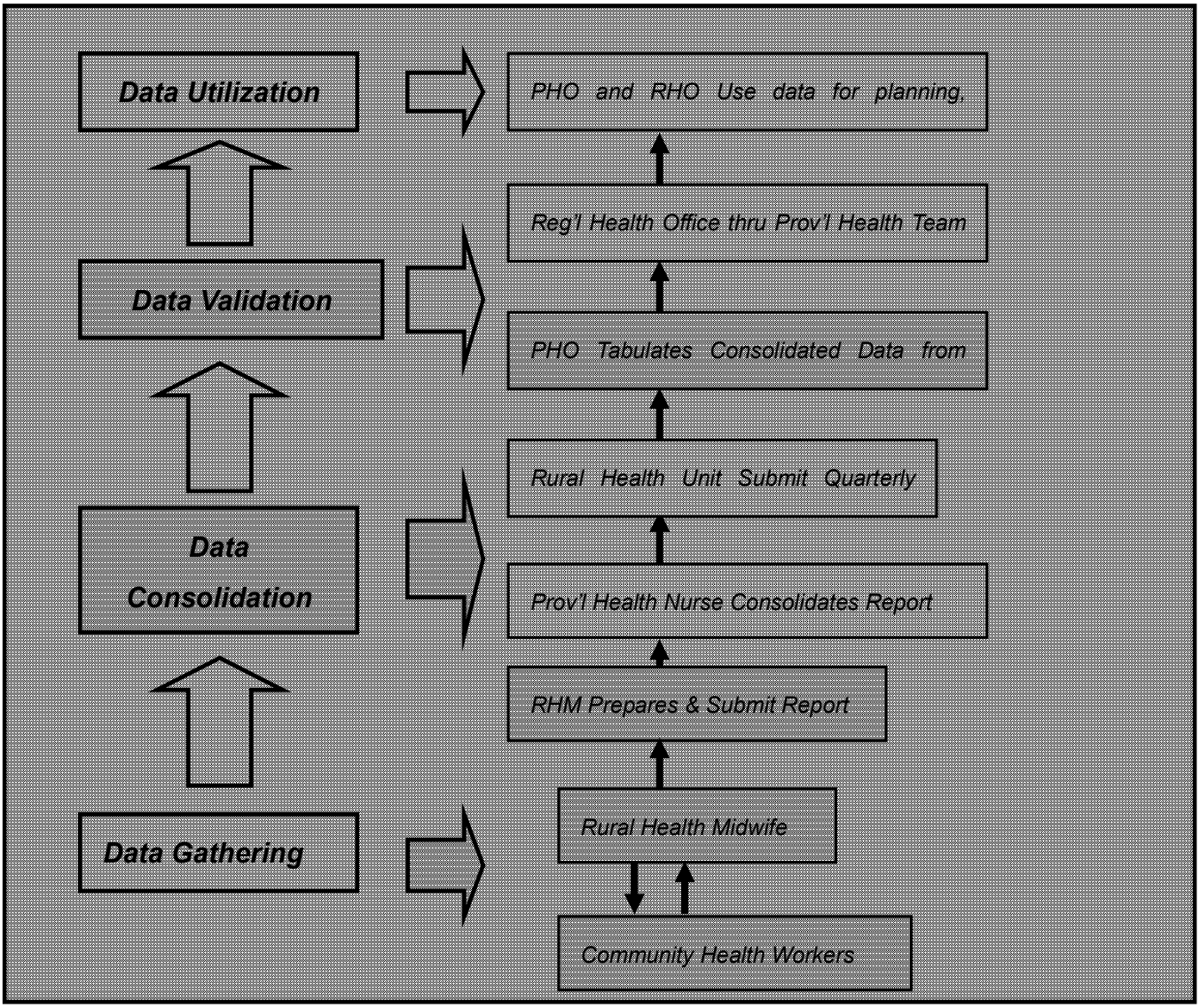

Figure 1. Diagram of Community Based Health Management Information System (CBMIS) in Camiguin. Figure 1 shows the system of data generation and management from the Provincial Health Office down to the municipal and barangay level. Community health workers employed by the local government in the CBMIS are called Barangay Health Workers. The system has been in place since the national reproductive health program began. The current flow of information has limitations and should be improved by ensuring more accurate and relevant data and usage.

extremely reliable and helpful in addressing unmet FP needs. This small-scale success indicates the considerable health benefits to be gained through a thorough, well maintained CBMIS.

6 Conclusion and Recommendations

While a CBMIS is in place at the PHO & RHU levels in Camiguin, current methods of generating and using data are inadequate to meet family planning needs in the rural areas. One type of shortcoming is inadequate techniques in data gathering and management. The other type of shortcoming stems from inadequate utilization of the existing information, due to low political priority for reproductive health.

Techniques in data gathering and management may be improved by better coordination and training of CHWs and RHMs. PRRM's experience mobilizing CHWs to maintain data boards in collaboration with LGUs suggests a basic model for effective community involvement. CBMIS implementation in other provinces in the region should also be reviewed. The bottom-up mechanism of program planning from village to municipal and provincial level should be retained, revitalizing the role of family planning providers and CHWs in providing reliable data for decision-making.

In improving the management information systems, the Provincial Health Office should consider the following: a) Eliminating unnecessary information, b) Improving feedback systems to use the information effectively, and c) Involving staff in the regular use of the information for planning, monitoring, and evaluating their activities.

In order for relevant information to reach many users, it should not only be forwarded to health facilities but also communicated in public meetings, social and religious gatherings. The feedback channels should provide prompt feedback from provincial and regional to local levels. However, the information gathered on individual households is highly personal, and strict confidentiality must be ensured to maintain clients' participation in the CBMIS.

Finally, it takes a great deal of effort, expertise, time, and money to create a management information system that produces comprehensive and integrated information on demand, but this is a worthwhile investment with anticipated long-term improvements in health governance. These improvements may also help reduce political obstacles by closely linking accurate health information to participatory planning.

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ABOUT THE AUTHORS

MR. KIMSORN SA, ILDC2004, Cambodia
Cambodian Youth Development Center (CYDC), Executive Director
Contact Address: Alongsdao Village, Kear Commune, Moung Russie District, Battambang Province, /P.O. Box 296 Battambang City, Cambodia
E-mail: cydc.org_kh@yahoo.com

MR. SUNARMAN, ILDC2004, Indonesia
Community Based Rehabilitation Development Training Center (CBR-DTC), Director
Contact Address: Jl. Lu. Adisucipto Km 7 Colomadu, Karanganyar, Surakarta 57176, Central Java, Indonesia
E-mail: cbr_center@indo.net.id, maman_shg@yahoo.com

MS. MARIE PRINCY, ILDC2009, Sri Lanka
Janawaboda Kendraya(JK), Programme Coordinator & Coordinator of Health Sector
Contact Address: No. 64, Chilaw Road, Negombo, Sri Lanka
E-mail: janawaboda@sltnet.lk

SR. NOEL CHRISTINE FERNANDO, ILDC1991, Sri Lanka
Sramabimani Kendraya (SK), Coordinator
Contact Address: 527/10 Suhada Mawatha, Liyanagemulla, Seeduwa, Sri Lanka;
E-mail: siddamal@sltnet.lk, sramabimani@sltnet.lk
URL:http://user3.nofeehost.com/suresh/sk/index.asp?Page=h

MS. WELIWERIYA LIYANAGE SUMIKA PERERA, ILDC2001, Sri Lanka
Women's Resource Center, Director,
Contact Address: No 74, Ayesha Watta, Yakalla, Ibbagamuwa,
E-mail: psumika@yahoo.com

Contributor (an AHI Newsletter Reader)

MR. RAYMUNDO C. AGATON JR, not AHI alumni, Philippines
Philippine Rural Reconstruction Movement (PRRM),
Camiguin Branch Manager
Contact Address: Maubog, Balbagon, Mambajao 9100 Camiguin, Philippines
E-mail: donagaton@yahoo.com URL: http://www.prrm.org/

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The Asian Health Institue（AHI）is a Japanese non-governmental voluntary organization committed to supporting the marginalized peoples of Asia. It acts both in Japan and abroad, to promote sustainable health for all in today's global village. AHI was founded in 1980 by Japanese Christian medical leaders who had served in several Asian countries. They realized that curative medical care alone was not a lasting solution to grassroots health problems. Instead, they saw a more effective and sustainable approach in training local leaders to promote community based action for health and development.

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THE ASIAN HEALTH INSTITUTE FOUNDATION (AHI)
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Tel: 81-561-73-1950 Fax: 81-561-73-1990 E-mail: info@ahi-japan.jp

Contact Person:
Kagumi Hayashi (Ms.), General Secretary, AHI

Editing and Advising:
Melisanda Berkowitz, Kyoko Shimizu, Shiori Ui, Mayumi Yamazaki and Kagumi Hayashi

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