PHAN TEE EAIN
(CREATIVE HOME)

The Three Millennium Development Goal Fund
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3MDG

COLLECTIVE VOICES:

UNDERSTANDING COMMUNITY HEALTH EXPERIENCES

Stage 1 Completion Report - August 2015

Phan Tee Eain

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Contents

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1. BACKGROUND

Introduction

In March 2015, the 3MDG Fund initiated "Collective Voices: Understanding Community Health Experiences" projects in partnership with six lead organizations to improve the understanding of the social factors limiting access to health care, and to support a meaningful participation of community members for better services and consumer satisfaction.

This initiative is to be implemented in two stages, in stage I focusing on building the strong relationship among target community areas and partner organizations, more understanding of issues relating to gender equity, social inclusion, community engagement, participation and health care access, and exposing them. The second stage will be designed to identify solutions to address the social barriers to health care identified in stage I and enhance capacity building of CBOs for improving community health care access. The first stage of the project commenced in March 2015 and was completed in August 2015. This report is based on stage I findings.

Phan Tee Eain is one of the six organisations selected to receive funding to increase health information and community voices to increase community health care access for disadvantaged groups (specifically poor women, girls and elderly women, women infected and affected by HIV, and lesbians and transgender groups). The Stage 1 project was focused on community level evidence collection through participatory approaches. PTE partnered with three Community Based Organizations (CBOs): Triangle Women Support Group, Colors Rainbow, and Rainbow Women's Organization.

The lead applicant, Phan Tee Eain, has been working on gender equality and women's participation in decision making at all levels in the social and political arena since 2009. The three partner CBOs have also been working with women, lesbian, and transgender groups in rights based programming for a minimum of 2 years. While working with these groups, we have all witnessed their limited access to information, health education, and available health services. They have no or very little power in decision making to make choices for their own health. Through the edutainment activities of our project, we aim to increase awareness and knowledge of the target groups in "gender inequalities in health", "what do fair and just health systems mean", and "what is the right to health".

One of the main strategies of Phan Tee Eain is to improve gender equality and good governance. Therefore PTE has practiced gender equality in its governance structure, staffing and target beneficiaries. PTE always tries to approach and practice accountability and gender equality in its all activities and actions.

Phan Tee Eain has a strong professional relationship with its three partner CBOs. Both Triangle Women Support Group and Rainbow Women's Organization are members of Women's Organizations Network (WON) in which Phan Tee Eain is currently the chair. Triangle Women Support Group and Phan Tee Eain have jointly organized big events such as Women's Forum, International Women's Day, and International Peace Day. Phan Tee Eain used to assist Rainbow Women's Organization in its organizational development and social business set up. Colors Rainbow has worked with Phan Tee Eain in its Domestic Violence Education program.

Project Summary

Central Goal: Improved access to quality health services for disadvantaged groups (poor women [young and elderly], women infected and affected by HIV, Lesbians, Transgender)

To achieve the central goal mentioned above, the project in Stage I focused on community level evidence collection through participatory approaches. Then in Stage II, the project has been designed to address the challenges that hinder access and promote greater access to appropriate health services in order to meet the specific health needs of each target group.

Phan Tee Eain is responsible for overall project management (including financial management) and reporting to 3MDG. Phan Tee Eain is the lead organization for this project. Three partner CBOs are responsible for working with target groups as shown in *Table 1: Three partner CBOs and their target groups*

Table 1. Three partner CBOs and their target groups

	Organization	Target group
1	Triangle Women Support Group	Poor women including young women, elderly women, and women headed households
2	Rainbow Women's Organization	Women infected and affected by HIV
3	Colors Rainbow	Lesbians and Transgender

In order to explore the real voices of the beneficiaries in Stage I, community meetings and edutainment programs were conducted in five target areas resulting in more understanding of the levels of health knowledge and social barriers experienced by the community. These meetings were facilitated by peer groups such as poor women [young and elderly], women infected and affected by HIV, Lesbians, and Transgender respectively. The participants in these meetings shared their experiences and feelings.

Key findings from Stage 1 included the discovery that the majority of the participants had never attended any kind of health talk or health education session. Further, a major social barrier to health access for Lesbians, Transgender and people living with HIV (PLHIV) is stigma and discrimination from families and society towards them. They had observed or experienced limited decision-making roles for women in the family relating to health care decisions. Moreover, effective and timely referral systems for Cervical Cancer, Opportunistic Infections and Prevention of Mother to Child Transmission needs to improve in the community. There were no health care services for elderly women and for HIV infected children especially counselling services. Reproductive Health knowledge is found to be incomprehensive such as misbelief related to menstruation in some girls, and limited knowledge about family planning among women. In addition, most of the PLHIV beneficiaries are suffering from socioeconomic consequences. Many of the participants were found to be influenced by traditional Myanmar medicine; and the “Harmful Social Norms” like scratching the skin with sharpeners during illness.

Details on these findings are discussed in the sections below. Based upon these barriers, the Stage II project will be designed to mitigate these social barriers and improve access to quality health care services for the beneficiaries.

2. OUTCOMES AND OUTPUTS

Outcome

The primary aim of Stage I was to identify community voices from project target areas concerning availability of health services and health seeking behaviour, elderly health care, stigma and discrimination, gender equality and decision making within a family on health issues including family planning, knowledge about sexual health, reproductive health (RH), communicable diseases such as HIV/AIDS, sexually transmitted infections (STIs), TB, Hepatitis B & C, and issues related to anti-retroviral treatment (ART) and Opportunistic Infection (OI).

This would then lead to Stage II, in which we identify solutions to address those social barriers to health care and enhance capacity building of CBOs for improving community health care access.

Outputs

1. Thirty peer group facilitators were selected and a camp with training for those facilitators was conducted to develop their knowledge of gender and health, sexuality, reproductive health, STIs and HIV, and capacity building to develop skills (e.g. facilitation skills) and an activity plan for the collection of community voices from targeted groups.
2. The respective community meetings were carried out at target areas as well as community edutainment sessions in those meetings to raise awareness about gender and health and to encourage community participation in the project.
3. Community voices were exposed and identified after conducting the community meetings.
4. A documentary film was developed to highlight key issues, voices, and edutainment representing each target group.

Activities for Outputs

Recruitment and skills development of peer group facilitators

Partners (Colors Rainbow, Triangle Women Support Group, and Rainbow Women's Organization) recruited peer group facilitators from the respective communities to collect information from the target groups. Colors Rainbow works with Lesbian and Transgender; Triangle Women Support Group works with poor women including young women, elderly women, and women headed households; Rainbow Women's Organization works with women infected and affected by HIV. A total of 30 peer group facilitators were recruited. Selection criteria were predetermined in line with the nature of the work.

Peer group facilitators were brought together in a camp setting for team building, project planning, and knowledge and skills building purposes.

The objectives of the camp workshop were: (1) to ensure everyone had the same understanding about the project while building the project team (2) to develop the knowledge and skills of the peer group facilitators in gender, gender specific health needs, right to health, sexuality, sexual and reproductive health, STIs and HIV, and facilitation methods (3) to develop peer group facilitators' activity plan together with the collection of IEC materials and the development of edutainment tools.

Photo 1: Camp and Training in Metta Centre, Bago

The dates of training, number of participants, number of resource persons and topics of the camp are shown in *Table1.*

Table1. Camp and training for peer group facilitators of three partner CBOs

Date	Training/Workshop Title	Training Location	No. of Attendance	Facilitators	Topics
May 3-9 2015	Collective Voices : Community Health Experiences (Stage-1) Camp and Training (7 days Training)	Bago Metta Centre	28 - participants 3 - focal persons (31 participants)	-U Aung Zaw Htwe, -U Hla Myat Tun (Colors Rainbow) -U Tin Aung Win, -Daw Myat Thandar Ko	Gender Sexuality Gender and Health (HIV/STI) Reproductive Health Facilitation and Skills Development

Community meetings and Individual Interview

The respective community meetings for project implementation were conducted from 8 to 21 June 2015 at five target areas. Edutainment and community meetings took place simultaneously. In these meetings, qualitative information was collected by means of brainstorming and participatory tools such as Nominal Group Analysis followed by Ten Seeds Technique, Group Interview and Discussion. Peer group facilitators of each partner CBO collected information from their respective target groups. For PLHIV target group used the both community meetings and individual interviews.

The objectives of collecting voices from the target populations were:

- To identify health seeking behaviour among target areas of each of the three partner CBOs
- To determine the accessibility of health services
- To assess the barriers to available health services
- To identify the gender differential in health services access

Approaches to explore Collective Voices

The information collection has been done in community meetings, collecting the community voices from the target populations in different areas or townships. These activities were carried out together with partner organizations.

Target population

The target population involved poor women and girls from Yangon (Dagon East/Seikkan), male and female people living with HIV/AIDS (PLHIV) from Dedaye and Yangon (Tamwe/Thingangyun), and Lesbians and Transgender (LBT) from Yangon and Lashio. A total of 85 groups participated in the community meetings of Collective Voices as shown in*Table2: Community Meetings and Table 3: Individual Interview*

Thematic Areas:

For women and girls group

- *Availability of Health Service and Health Seeking Behaviour*
- *Elderly health*
- *Decision making for health seeking practices*
- *General Reproductive Health Information, Delivery Practice and Contraception and Use of Condoms*

For LBT group

- *Barriers in Accessing Health Services including Stigma and Discrimination*
- *Decision Making for Health Seeking Practices*
- *General Reproductive Health Information*
- *Contraception and Use of Condoms*

For PLHIV group

- *Barriers in Accessing Health Services including Stigma and Discrimination*
- *Decision Making for Health Seeking Practices*
- *Health Seeking Behaviour Related to ART and OI*
- *Knowledge on HIV/ AIDS Including Mode of Transmission and Prevention*
- *Contraception and Use of Condoms, Ante-natal care and Prevention of Mother to Child transmission (PMCT) services Family support*
- *Delivery practices*

Table 2: Community Meetings

No.	Date	CBO	Township	No. of Attendance	Type of Participants
1	8.6.2015	Triangle Women Support Group	Yangon Dagon(East/Seikkan)	34 - participants	20 women, 14 girls
2	14.6.2015	Rainbow Women's Organization	Dedaye	11 - participants	4 men, 7 women
3	18.6.2015	Colors Rainbow	Lashio	18 - participants	1 Lesbian , 3 Trans Men, 7 Gay, 7 Trans Women
4	20.6.2015	Colors Rainbow	Yangon	10 - participants	1 Lesbian, 2 Trans Men, 7 Trans Women
5	21.6.2015	Rainbow Women's Organization	Yangon Tamwe, Thingangyun	12 - participants	7 men, 5 women
			Total	85 - participants	

Table 3: Individual Interview

No.	Date	CBO	Township	No. of Attendance	Type of Participants
2	14.6.2015	Rainbow Women's Organization	Dedaye	4 - participants	1 Man and 3 Women
5	21.6.2015	Rainbow Women's Organization	Yangon Tamwe, Thingangyun	3 - participants	1 Man and 2 Women
			Total	7 - participants	

Edutainment in respective communities

Colors Rainbow has been performing edutainment at the community level within their constituencies for 2 years. Colors Rainbow works with Triangle Women Support Group, and Rainbow Women's Organization and peer group facilitators for community level edutainment to raise awareness on gender and health, and to encourage community participation in the project.

Edutainment was conducted 5 times in respective community meetings at 5 places within the project area, with the last session being *Participatory Education Theatre* (Community Meetings details in Table 2). A focal person of Colors Rainbow facilitated this session and twelve people performed and participated in the performance at all meetings. In the Tamwe and Dedaye community meetings, some of the performers (peers of PLHIV group from Colors Rainbow) joined with to perform in their target area.

In every meeting, a role play was conducted with community participants (audience) as Participatory Educational Theatre. In each project area, 4 or 6 role play topics were covered in each session. The topics were:

- how pregnant women should deliver, including with a traditional birth assistant, midwives or at hospital
- contraception knowledge and discussion of family planning with partners
- lack of specialised health services for the elderly
- changes to and misuse of ART treatment
- suffering from stigma and discrimination by family, school life and surrounding environment etc.

In every community meeting, these topics were explored through the Edutainment Session with participation by all community participants.

Photo 2: Edutainment Session in Community Meeting at Lashio Township, Shan State

Documentary Film making, editing, and production

Voices representing each target group and highlighting key issues were recorded. Colors Rainbow led the Documentary Film process for all meetings. This film was recorded while community meetings were conducted in target areas. Colors Rainbow had existing capacity to take charge of the documentary filming, and they brought an expert (Tagu Films) for documentary film editing. Documentary film editing was carried out in the last week of July 2015 and was produced as an interesting, complementary record of project outcomes with this project report for stage I.

Monitoring activities

A joint monitoring team was established, comprising representatives from Phan Tee Eain, Colors Rainbow, Triangle Women Support Group, and Rainbow Women's Organization. A detailed plan for project monitoring was developed during the camp workshop. The joint monitoring team was responsible for tracking the project progress, providing necessary support and guidance to project focal persons and peer group facilitators. Monitoring visits took place during the project period in project locations.

Monitoring visit plan:

- Target area - 4visits/meetings:
  2 in Yangon, 1 in Lashio, 1 in Dedaye
- Target date - took place last week of July and first week of August

Monitoring and Evaluation (M&E) activities carried out by PTE aimed to review project activities to ensure successful inputs, outputs and outcomes to reach specific objectives and goals, including assessing whether community meetings were conducted in targeted areas or not and reflected voices from participants of community meetings through interviewing, questionnaires, edutainment sessions and IEC materials.

3. KEY FINDINGS

The key needs and social barriers discovered in our community meetings of Stage I, identified and collected by our peer group facilitators, are as follows:

Women and girls group

Availability of Health Services and Health Seeking Behaviour

All four groups of women and girls mentioned that there are some Charity Clinics where they can seek health care free of charge at their townships and most the people are using those services when they get ill or experience any other health problems. The popular Charity Clinics are U Kyaw Thu Clinic, Ah-Mae Myitta Clinic, Ah-Mae Eain NLD Clinic, Shwe Pyay Hein Clinic, Yazakyoe Monastic Charity Clinic and BG blood Donation Group.

Some of the participants stated that they seek care from private clinics nearby and sometimes buy some medicines from nearby drug shops where drug-sellers give treatment and some medicines for short-term illness.

Elderly Health

Elderly health care was not highly prioritized in the community. Community members explained that there is no government elderly health care centre in their townships. The elderly have to go to the general hospital when ill. The following common illnesses for the elderly were identified in the four group discussions -back pain, unspecified abdominal pain, dizziness, mental health problems, cancer, hypertension, heart disease, stroke, diabetes, anaemia and related illnesses.

Photo 3: Community Meeting in Dagon (East/Seikkan) Township, Yangon Region

Decision Making for Health Seeking Practices

Regarding decision making in the family related to health and health care for family members, most of the participants identified fathers as the key decision makers because they work outside of the home and earn the money that the family needs for the household. Only a small portion of decisions are made by mothers who spend more time with family members. Other decision makers are grandparents, self, and other relatives such as an aunty or uncle.

General Reproductive Health Information, Delivery Practices, Contraception and Use of Condoms

The following common illnesses for women were identified by the four women and girls groups during the interviews and discussions - breast cancer and cervical cancer, reproductive tract infection, hypertension, Hepatitis B and C, gynaecological problems and abdominal pain or stomach problems.

Photo 4: Edutainment Session in Community Meeting at Dagon (East/Seikkan) Township, Yangon Region

All women and girls stated that female reproductive health problems and gynaecological problems are common for females to face, and therefore they should not feel ashamed. Family members should know more about these problems in order to get suggestions and support about how to solve the problems and get early diagnosis and treatment.

> The perception and general knowledge on puberty was mostly correct, albeit with some traditional beliefs still present. Mothers and grandmothers are the key people that girls prefer to discuss these issues with, while friends are considered the closet person with whom they can talk freely and share experiences of puberty. One of the girls from girls group stated: *"Mom is my consultant for changes in puberty, how to stay with menstruation, what to eat and not to eat. She also suggested that I should remember the date of my period and not wash my hair during period."*
>
> (A girl from girls group)

Misbeliefs such as "the blood flow during a period is due to bad blood in the body coming out monthly to finish all the bad blood" was identified in one of the groups. However, the other group could explain correctly why menstruation happens, saying that "it is due to changes in hormone level and bodily changes are also based on that hormonal changes." Otherwise the general knowledge and perception of menstruation is correct and acceptable.

Regarding knowledge on cervical cancer, the majority of women and girls said that cancer of the uterus and cancer of the cervix is not the same, which is the correct understanding of the difference between these two cancers. However none of them had been tested for cervical cancer. They know that it can be screened and it should be, but have not done that before. The common reasons are that women do not know where to go for screening, do not have enough money, the doctors do not have many appointment times, they are afraid of knowing the results, and have no time to go for screening.

Findings from women and girls groups identified that most of the pregnant mothers deliver at home, or township hospital in their area. They consult with their husband or mothers for pregnancy related issues and health seeking practices.

Among the women and girls groups, some recently married girls said that they do not want to have children immediately after they marry. They use contraception and consult with their husband or midwife or other married friends. They said some girls do not have enough knowledge of contraception and are having many children one after another. There are some health education sessions or talks given on topics like contraception, such as available contraception, pros and cons, choice of contraception, etc. However only a few of them attend such health talks because most of them do not know about it.

All women and girls mentioned the common contraceptive methods as follows:

1. Three monthly depo injection
2. One monthly depo injection
3. Daily contraceptive pills
4. Condom
5. Intra-uterine contraceptive device (IUD)
6. Sub-cutaneous contraceptive implant

But some of them do not know about the correct timing of these methods, how to use them properly and the advantages and disadvantages of the various methods. They also do not have sufficient knowledge to make informed choices about the methods most suitable for them.

LBT group

Barriers in Accessing Health Services including Stigma and Discrimination

The main barriers in accessing health services for the LBT group were related to their sexual preferences and related behaviours. Although they are biologically male or female, their sexual preference is different to the expected social norms based on their biological determination. In this case, the main barrier in *accessing health services in the community for them was stigma and discrimination*. Through group discussions with the LBT community they explained that when they go to the clinic for STI diagnosis and treatment, HIV counselling or testing, or any other health services, they are assumed to already have such kinds of diseases because of their 'risky' sexual behaviour.

Photo 5: Community Meeting in Lashio Township, Shan State

"…it was said in the community that I may get HIV because I'm a transgender person. Living together with another man is not acceptable in our community. People look down on us. Even to get counselling and testing, it does not feel very convenient or comfortable for us sometimes, especially if the medical doctor at the clinic is a female; then, I feel shy to consult with her and to show her my private parts if needed."

(A Transgender participant from the group discussion)

Many of the participants from LBT groups reported that stigma and discrimination was the main problem they faced in the community as well as from their family and among friends.

One of the participants from the group discussion mentioned that being biologically male but wanting to be a female resulted in discrimination from his family, the community and friends. This was a common finding among the LBT groups.

"…my family has only one child. I'm a boy, but I want to be like a girl. I love girls' dresses and to prepare myself like a girl. My family always spoiled me whenever I dress like a girl. When I was dressed only with a boy's clothing, I was forced to play like a boy – e.g. football."

(A participant from LBT group)

"…my father doesn't like me behaving or dressing like a girl. When I go outside, I sometimes wear clothes like a girl, but never at home. Sometimes, my father beats me when he sees me wearing clothes like a girl. He said 'get out of my home if you make MSM friends'. Also among my friends, I was called 'Ah-chout', and teased by some friends. " (a participant from LBT group)

Photo6: Community Meeting in Yangon, Yangon Region

Similarly in the biologically female groups, the findings from the group discussion were that many experience stigma and discrimination from the community, at school and from family members. They were told that they are not suited to the community environment by wanting to be a man although being female.

> *"…when I was a student, my parents put me at the female only school. I was so disappointed when I had to wear the female school uniform and hade to dress like a girl. I wanted to be like a boy. When I behaved like a boy, even my teacher discriminated against me and looked down on me compared to other students, saying that I'm a girl but wanted to be a boy, what's the point? Friends in my class also didn't like me. Later on, I was not happy to go to the school and missed school…."*
>
> (A participant from LBT group discussion)

Decision Making for Health Seeking Practices

In the LBT groups, decision-making for health seeking and choices of accessing health care were made by themselves mainly. There was less influence by the family or their partners in decision making related to health care. It was reported in the group discussion that the socio-economic situation could also influence the decision-making in the choice of health care for the LBT group, i.e., if they have the better economic situation, they might choose better health care services. Overall health seeking knowledge and practices were found to be positive in the group discussions in all study townships.

General Reproductive Health Information

In this session, general reproductive health information in LBT groups was discussed from two different perspectives based on their biological sexual identity regardless of their sexual preference.

For those who are biologically male, the participants from the group discussion reported that they had basic knowledge of puberty changes and the functions of reproductive health organs. The participants also mentioned that they had knowledge of sexually transmitted infections, modes of transmission, prevention methods and use of condoms. They also knew about availability of HIV counselling and testing and the frequency of HIV testing they should take as the at-risk persons. The participants also understood that they should consult with medical doctors if they had any concern about STIs and should be treated well together with their partners. In relation to health seeking practices, they also knew that INGO clinics at their townships were providing services.

Based on the Ten Seeds activity, the following were the most common findings about their general reproductive health knowledge:

- If you have an exposure to sexual risk, you have to take HIV tests three monthly
- Knowing the risks of using female hormones but they do not really know side effects of hormone tablets.
- HIV is one of the important STIs
- In both oral and anal sex, condoms must be used
- They feel looked down on for being LBT
- Condoms must be used in every sexual practice/ exposure
- It is better to reduce sexual exposure
- There is a need for a good counsellor to consult privately about their sexual practices

For those who are biologically female, the participants from the group discussion reported that they understood their puberty changes, but they did not want to experience biological changes for their body, and they wanted the opposite changes. They also mentioned that they felt uncomfortable when they had their menstruation cycle. The participants also reported that they had some knowledge of general reproductive health related to female characteristics. The risk of having sexually transmitted infections was

also mentioned in the discussion. Using the Ten Seeds method, were the most common findings about their general reproductive health knowledge:

- They do not want female characteristics such as breast enlargement
- They can accept the menstruation cycle as one female characteristic but if possible, they do not want to get the cycle
- They know the risk and side effects of using male hormones to some extent, but they do not also really know about bad side effects of hormone tablets.
- Sometimes, they suffer from irregular menstruation
- Personal hygiene is important including using clean underwear

Contraception and Use of Condom

LBT groups reported that they also used condoms when they had sexual exposure, but there were some times when they missed using a condom, such as when the condoms were not easily available, when the partners did not want to use condoms, and when they believed in their partners and assumed that he/ she might not have HIV or an STI.

Some of the LBT mentioned that they used hormonal drugs (e.g. females wanted to use male hormones, and males wanted to use female hormones). Some of them stated that they understood the risks and side effects of using sexually opposite hormonal drugs for their sexual behaviour and desires for changing their body's appearance.

PLHIV group

Health Seeking Behaviour, Barriers in Accessing Health Services including Stigma and Discrimination

This session only explored the views of PLHIV. Almost all the participants stated that they knew that ART is a life-long daily treatment and they have to take the medicine for their whole life once they have started. It was also mentioned that they cannot miss a dose of ART because it will lead to drug resistance. The participants also had some knowledge on the side effect of ART treatment. The common side effects they mentioned were nausea, vomiting, and weight loss, lipolysis, malaise, palpitation and dizziness. Most of them said that they normally take the medicine at night 7pm or 8pm, and 7am-7pm regime for those taking the drug twice a day.

Photo 7: Individual Interview in Dedaye Township, Ayeyarwady Region

All of the participants from the PLHIV group were taking ART from the hospital or clinic from *another township, not from Dedaye township hospital*. It was found that there is no INGO clinic giving ART at Dedaye Township. Dedaye hospital is giving ART starting only a few months ago. *There is no one who is taking ART treatment at Dedaye hospital although there is ART treatment available at Dedaye hospital. It was suggested that there might be some PLHIV at their townships who are not going to take any treatment. This might be due to shyness and feeling afraid of discrimination from the community about being the PLHIV.*

Therefore one of the main barriers from the participants was the time for travel and transportation costs from Dedaye to another township to get ART. Mostly, they were taking ART from Yangon Thaketa hospital, Yangon Central Women hospital, Thazin clinic, Mingalardone hospital, Pharpone township hospital and Maubin township hospital.

> *"…the main barrier for me is travel. I have to go to Yangon to take ART every month. The travel cost is normally about 30,000 kyats per visit. It is also time consuming. I need to stay my friend's house for one or two nights, and I have to miss my work during the days that I'm going to get the ART."*
>
> (A 50 year old male PLHIV)

> *"…waiting time is also one of the main barriers for us. I have to go to the clinic/ hospital in the early morning before 7am, the doctors arrive at 8:30 or 9am, ….then we have to wait for the doctors and finally we finish all the procedure for one day at around 12:30 or 1pm… go back home can't do any work for that day!!…."*
>
> (A 42 year old female PLHIV)

The economic and social consequence in the family is one of the barriers for the participants. It was mentioned in the interview that the family sometimes pays less attention to the PLHIV due to the treatment and health care costs as well as missed work, leading to economic burden and less income.

> *"…when I became HIV positive, my wife took all my business. I was going to the hospital and caring for myself to get ART. The household income was low and one of my children had to leave school to help my wife in the shop. These are also barriers for me, especially from the perspective of economic burden…. "*
>
> (A 33 year old male PLHIV)

The major barriers in the accessing health services and taking ART treatment for PLHIV people were transportation, costs for transportation, economic barriers, and social barriers, waiting times at the hospital for taking ART, and timing and duration of travel to get to the hospital.

Photo 8: Community meeting in Tamwe Township, Yangon Region

We identified *stigma and discrimination* towards PLHIV at hospitals, in the community, in the family and amongst relatives. At the hospital, the participants mentioned that the communication of hospital staff (doctors and nurses, etc.) was not good; sometimes the staff would yell and not talk properly to them. Sometimes they needed to give money to helper staff. It was said that the participants were treated improperly at the hospitals sometimes, such as, staff not wanting to touch them, using extra precaution, extra charges/ cost for care and treatment, etc. There was also a problem of doctor patient ratios; many HIV patients and less doctors, leading to prolonged waiting time for the patients. Sometimes PLHIV patients were isolated at the hospital with less attention.

> *"…when I was at the hospital with complaints of abdominal pain during pregnancy, the hospital staff, especially nurses put me aside from the other patients, provided less care and took extra precaution using many gloves. They treated me poorly at the time of treatment…I was feeling sorry for being treated like that…I'm the same like other patients and was discriminated against…. "*
>
> (A 37 year old female PLHIV)

In the community, the participants also mentioned that there was some level of *stigma and discrimination* such as people not wanting to talk to them and wanting to stay away from them. Therefore PLHIV also do not want to let his/ her status be known to the community. One of the female participants experienced the following:

> *"…I was selling pork meat at the market. When people knew that I had HIV, they said 'don't buy the things from her, she is HIV positive and can infect drugs from her'…I was so depressed…."* (A 30 year old female PLHIV)
>
> *"……my family treated me very differently when I was diagnosed as PLHIV. They didn't want me to use the household material such as plates, spoons, etc. with me together. Even my mom and my sister didn't want to come to me at the early days of diagnosis…I was so depressed…now they can understand that HIV cannot be transmitted by contact…a bit better compared to before…"*
>
> (A 33 year old male PLHIV)

As the social and economic consequences, children from the PLHIV household had to drop out from school to help their parents, due to hospital costs and health care costs.

Decision Making for Health Seeking Practices

In PLHIV interviews, the decision making for health seeking practices was based on the availability and accessibility of ART treatment for them and socio-economic status of the family. They had to go the health facilities where they can get ART. Family support and decisions or suggestions by the head of the family, such as the husband or mothers, were key factors in decision making in health seeking practices, especially for the female PLHIV.

Health Seeking Behaviours Related to ART and OI

Counselling was also discussed in the in-depth interviews. The participants knew that they had to get counselling at least three times to get ART drugs. They said that some the explanations related to counselling were not sufficient. Mostly the NGO clinics were providing counselling properly, but not at the government hospitals. The reasons might be due to the high workload at the government hospitals, mentioned by one of the participants. It was also found that there is no specific counselling for children's cases at the hospital. On the other hand, counselling was not well practiced for old ART patients.

> *"….I tried to get some information about my son who is also PLHIV. He is only 4 years old. But there is no specific counselling session for children and doctors didn't explain to me clearly what to do and how to do for my son…."*
>
> (A 50 year old female PLHIV)

> *"……at the start, counselling was done for me, but now as an old patient, counselling was not done properly. If I want to know something, I have to go and ask the doctors, but they are mostly very busy and cannot pay attention to me….."*
>
> (A 33 year old male PLHIV)

Most of the participants did not know what opportunistic infection (OI) is and how to prevent and treat OI. However some of them were taking drugs such as Spetrin for the prevention of OI. They mentioned that most of the OI drugs were given by the INGO clinics, such as Thazin clinic.

> *"…the hospital gave me some drugs, not only ART, but also other drugs, but I don't know exactly what these drugs are for…."*
>
> (A 50 year old male PLHIV)

> *…"if HIV positive, OI will come along. If you don't take regular medicine, CD4 count will be decreased and I will be ill…."*
>
> (A 33 year old male PLHIV)

Story from a female sex worker (in-depth interview) is shown in the Annexes. (Annex 4)

All of the participants did not know exactly what ART and ARV are. Some of the participants indicated that they took traditional medicine together with western medicine for the treatment of HIV. It was mentioned that there was no cost for CD4 testing at the hospital. Most of the participants stated that they have some knowledge about the CD4 testing; such as it is measuring the body resistance and immunity status and the normal range would be between 800-1200. However they had no knowledge on the viral load and no one had been tested for viral load in the study population.

Knowledge on HIV/ AIDS Including Mode of Transmission and Prevention

The knowledge on HIV/AIDS including mode of transmission and prevention methods were explored in the in-depth interviews (IDI) with PLHIV participants and their household members. All participants from the IDI stated they knew very well that HIV and AIDS are not the same; HIV is the name of virus and AIDS is the syndrome disease. They also knew that HIV cannot be cured, but one of the participants mentioned that it can be cured in foreign countries.

> *".....I heard that in other foreign countries, it can be cured. But it's not reachable for our country……"* (A 50 year old female PLHIV)

Most of the participants from the IDI mentioned that they knew the mode of transmission of HIV correctly; by blood transfusion, contaminated blood and blood products, contaminated needle and syringe, mother to child transmission, breast feeding by HIV positive mother and sexual transmission without using condoms.

Regarding the prevention methods, the participants from the IDI could identify prevention methods such as taking ART, using condoms during sexual activities, taking care of bleeding when having injuries, good personal hygiene, and good nutrition, single use of shaving materials and using disposable needles and syringes for injections. However no one mentioned their perception on the major mode of transmission in the interviews.

Diagnosis of HIV

This issue of HIV diagnosis was only explored in the PLHIV groups. For the female PLHIV participants, four out of five female participants said that they were diagnosed at the time of an antenatal care visit to the hospital or health facility. One of the participants was diagnosed after her husband was diagnosed with HIV. Both male PLHIV participants were diagnosed as tuberculosis patients first, followed by a diagnosis of HIV.

They felt sorry and depressed as soon as they were diagnosed as HIV positive persons. One of the participants attempted suicide once when she was diagnosed with HIV. One of the male PLHIV who was recently diagnosed mentioned the following in the interview:

> *"Whether we take medicine or not…… we will die with HIV to AIDS one day."*
>
> (A 33 year old male PLHIV)

Family Support

This issue of family support was only explored in the PLHIV groups. The main type of family support mentioned in the group discussions and by the IDI participants from the PLHIV group were family members accompanying them to the hospital, reminding them to take medicine regularly, and providing daily and psychosocial support. Key persons who helped to mainly remind the PLHIV to take medicine at home were the husband, mother, wife, children, mother-in-law and sister. One participant stated that he was reminded by using an alarm and writing on the wall to remind himself not to forget to take the medicine. Some of the quotations regarding the family support were as follows:

> *"…my youngest son always reminds me to take the drug when it is time even though I use an alarm to take the drugs…."*
>
> (A 50 year old female PLHIV)

> *"..when I was first diagnosed, I felt lonely and depressed. I cried daily for nearly a month….my husband is the one who stayed with me and gave me support. He said there are many people like me and I'm not the only one. Just take the drugs regularly and don't be feeling depressed….he is also HIV positive…"*
>
> (A 37 year old female PLHIV)

Knowledge on TB, STI and Hepatitis B, C

In the PLHIV groups, participants had some level of knowledge regarding tuberculosis. They mentioned that TB can be experienced together with HIV, and if present, the patient must be taking treatment for at least 6 months. Some of the participants already had taken TB treatment at the time of diagnosis of HIV.

They also had knowledge of sexually transmitted diseases, the mode of transmission and some of the treatment durations for STIs. One of the participants had already taken STI treatment before. Compared to knowledge on TB, the level of knowledge on STIs was less than TB based on the findings. However, they had no knowledge of Hepatitis B and C.

There was very limited knowledge on TB, and Hepatitis B, C in women and girls groups and LBT groups. Some knowledge on STIs was found in the LBT groups and discussed in the above session.

Antenatal Care and PMCT Services

Antenatal care and Prevention of Mother to Child Transmission (PMCT) services were discussed among the women and girls groups, and PLHIV groups, but not in the LBT groups.

Regarding antenatal care and delivery, the women's group mentioned that pregnant mothers should go for antenatal care as soon as they know they are pregnant. The recommended month of pregnancy to go regularly for visits is the fourth month. Pregnant mothers normally go to the clinics or health care centres in their townships. Some of them consult with midwives at their place. They know to do some blood testing during pregnancy but only a few of them correctly know what kind of blood testing should be done, such as blood testing for HIV, STIs and blood group testing.

In the PLHIV groups and interviews, participants mentioned that antenatal care was mostly done with midwives and PMCT services were available at the government hospital, mainly the central women's hospital and township hospital at Dedaye Township. They had some level of knowledge regarding PMCT services and care for children from HIV positive mothers. It was found that there were four places where PMCT services and delivery for PMCT were available – Central Women Hospital, North Okkalapa Hospital, Insein Hospital and Thingangyun Sanpya Hospital. Generally both males and females know about PMCT but they are suffering from stigma and discrimination by health staff. Only few of them have received the correct treatment.

Delivery Practice

From the PLHIV group discussion and interviews it was found that five out of six women from the IDI had experienced hospital delivery with PMCT services. Participants mentioned that at Mingalardone Specialist Hospital, PMCT services were not properly recommended for or explained to the patient. One of the women delivered her baby at home with normal delivery because she had no time to go to the hospital and arrived at the hospital after birth. Otherwise, they had sufficient knowledge about the need to get PMCT services. This might be due to the fact that they were also diagnosed at the time of their antenatal care visit. Knowledge on breastfeeding was also good, with participants saying that they can breastfeed until 6 months after birth and then switch to milk powder. However the use of milk powder can create a high cost of around 100,000 per month for rural women.

Contraception and Use of Condom

Based on the PLHIV group discussion and interviews, participants also knew that using condoms can provide dual protection - contraception and prevention of sexually transmitted diseases. Female PLHIV mostly used condoms with their husband.

"I use condom as the primary prevention for the contraception method to prevent another pregnancy….. I don't want to get another child…." (A 42 year old female PLHIV)

Gender

Women and girls groups, LBT groups and PLHIV groups

In the gender exercise, playing a game of Rice Distribution and a Running game was carried out. These exercises explored the gender differences and gender issues in all groups. For all groups, the Rice Distribution game was used. In the game, the participants distributed one pot of rice for the people in their household (in Myanmar units, there are eight small pots for one pot of rice).
The findings in the **women and girls groups** are as follows:

Person	Group 1 (girl)	Group 2 (women)	Group 3 (women)	Group 4 (girl)
Pregnant mother	2	3	3	4
Father	4	3	2	3
12 year old child	1	1.5	2	0.5
2.5 year old child	1	0.5	1	0.5

The rice was distributed mainly to pregnant mothers and fathers in the household. However, not all of them gave the largest portion of rice to the pregnant mother. One group gave the largest proportion to the father. This exercise showed that there is some gender bias in the family, rather than looking at the equity of distribution in the family. It was seen that the father is prioritized in that group. In **PLHIV groups**, all of the participants gave the largest portion of rice to the pregnant mother. Findings from the **LBT groups** were the same as above in the women and girls groups.

We used Running games for the LBT groups. For the Running game, participants were asked who should be in the 1st lane to 4th lane in the running path. The participants had to decide in a group whom they would put in the 1st lane to 4th lane. The 1st lane meant being in first place and getting more chance to get nearer to the goal, followed by the 2nd, 3rd and 4th lane respectively. This game reflected gender differentials and their ideas and perceptions about how the different participants thought about gender issues.

RUNNING GAME				
Person	**Group 1**	**Group 2**	**Group 3**	**Group 4**
Transgender	1st lane	2nd lane	Equal	1st lane
Lesbian	2nd lane	4th lane	Equal	3rd lane
14 year disabled old boy	3rd lane	3rd lane	Equal	4th lane
6 year old boy	4th lane	1st lane	Equal	2nd lane

Key barriers to be prioritized

- Most of the target groups seldom go to the government hospitals; instead, they go to Charity Free Clinics and buy drugs from small drug stores. Stigma and discrimination from families, society and some health care providers towards minorities like LBT people was significant.
- Most target group members are generally influenced by traditional Myanmar medicine; and the "Harmful Social Norms" from influential persons of the family are quite common.
- Communities were found to have limited knowledge about sexual and reproductive health, communicable diseases, such as HIV/AIDS, STD, TB, Hepatitis B and C. They do not have knowledge on family planning as well. They do not have enough money for medical expenses either.
- The decision making role of women in their family for health issues including family planning was found to be limited. Key decision makers for health issues are fathers, the breadwinners of the families. Only a small portion of decision-making goes to mothers who spend more time with family members.
- The knowledge of LBTs regarding hormones was incomprehensive. LBTs mostly suffer from stigma and discrimination in all surroundings: home, school, workplace, etc. They have no friendly services for health care. They take hormone tablets without knowing the side effects of them.

- There is a weak referral system for accessing health care services including Voluntary Confidential Counselling and Testing, PMCT, OI, ART AND CD4 testing. The main barrier in this case is stigma and discrimination from society including health care providers.
- There are no health care facilities for elderly women.
- Gender equality needs to be improved among target beneficiaries. The breadwinner of the household controls the power in the family, taking the influential role in the family.

From these findings, it was obvious that people needed to be sensitized to reduce stigma and discrimination towards those marginalized groups such as LBT, poor women and girls, and PLHIV women and their families. Only when those groups are free from stigma and discrimination from society, can they fully enjoy their rights to health. The health knowledge on diseases, drugs and health seeking behaviour of those targeted populations needs to improve to reduce their harmful social norms and to get better health for all.

In addition, it is clearly very important to make the community more aware of the available public and private health care services available to them. For example, there is a need for referring clients to places where they can get health care services and providing them with information about how they can get there. Moreover, it is necessary to support health care providers to be able to reach the unreached community.

In other words, a buffer between health care providers and the community is really needed to reduce the misunderstandings between them. Last but not least, efforts are needed to ensure that women in the community have improved decision making roles and capacity within their families leading to gender equality in Myanmar society.

4. GOOD PRACTICES & LESSONS LEARNED

The purpose of conducting the camp and training for peer group facilitators of each partner CBO was to give them knowledge on health, facilitation skills, participatory skills and establish good relationships with, and communication among, partners, participants, trainers, and organizers. They would then collect information from respective target groups.

By conducting this camp, the peer facilitators could conduct the community meetings successfully. To be able to successfully carry out the conducted camp and training for peer groups facilitators, the implementation process needed to be well planned in the early stage of the project. For example – to access the experience of the resource persons, to seriously consider place, time, budget and unexpected conditions such as unfavourable weather and disastrous problems.

Although target populations included tentative numbers of participants from different target groups of the communities, the number of lesbians who had been interviewed was less than expected. Thus, we should consider this factor as a risk and plan risk mitigation plan for this issue in future. For example, we should expand targeted project sites to get more beneficiaries.

Recommendations

Collectively, the project results suggest the need to have better health for all in targeted project sites. There should be a program to reduce stigma and discrimination towards marginalized people like LBT, poor women and girls, and PLHIV and their families. Hence, awareness-raising activates about them such as edutainment programs and Information, Education and Communication (IEC) are highly recommended to overcome this social barrier in society.

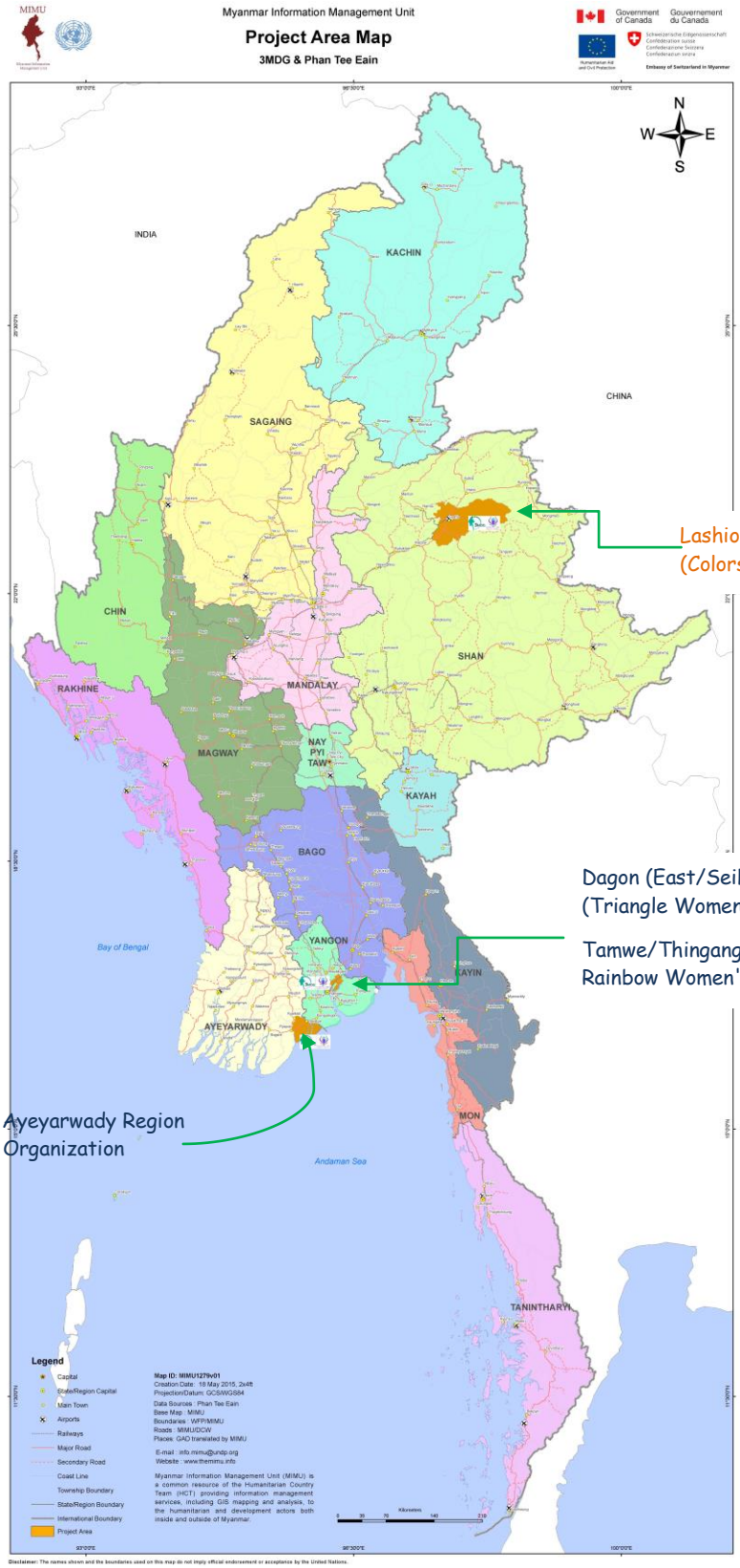
Moreover, those targeted populations should be empowered to build their self-esteem which can lead to empowerment. Thus, PTE suggests developing a group called Community Health Groups (CHGs) comprising of these beneficiaries. These CHGs will improve health knowledge and health seeking behaviour of the community by conducting health education sessions, men engagement activities and home visiting to improve access to updated and accurate health information of those beneficiaries. This type of program can achieve gender equality as well as improvement in health knowledge and health seeking behaviour at the same time.

Partnership and networking needs to be considered as a very important recommendation from these Stage 1 findings. To be specific, effective and efficient referral system to direct people to public and private quality health care facilities should be well established in these areas. Thus, the whole community can access health care services and enjoy their rights. On top of that, coordination with the public and private sector such as attending coordination meetings and supporting Basic Health Staff in their activities should be promoted to fill the gaps and avoid overlapping.

In addition to the above recommendations, the community themselves suggested a couple of facts. There should be more charity clinics in their townships for poor and needy families. They suggested to the facilitator the need to have quality health care such as comprehensive counselling services, short waiting times and easy access to ART clinics. High medical expenses are also a barrier to health care for the poor community. Therefore socioeconomic barriers should be considered as a priority, including limited health knowledge.

5. ANNEXES

Annex I – Phan Tee Eain Project Map



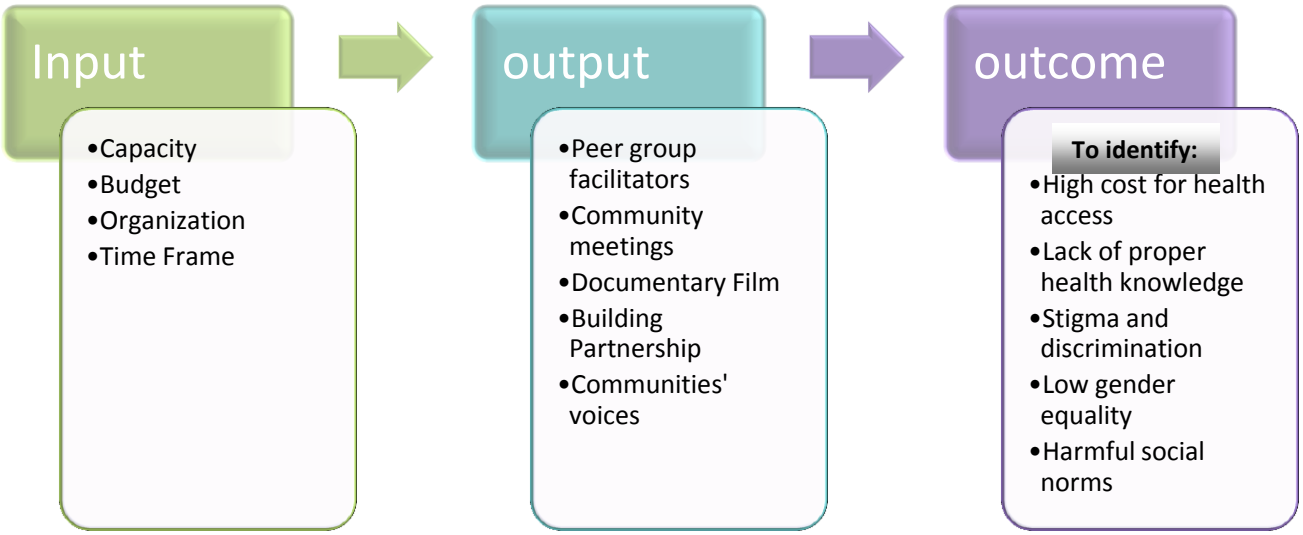
Lashio Township, Shan State
(Colors Rainbow)

Dagon (East/Seikkan) Township, Yangon Region
(Triangle Women Support Group)

Tamwe/Thingangyun Township, Yangon Region
Rainbow Women's Organization

Dedaye Township, Ayeyarwady Region
Rainbow Women's Organization

Annex II – Flow Chart of Community Voices



Annex III – Background Characteristics

The mean age of participants and background characteristics from different target groups are shown in the following tables.

Table 3. Age distribution of participants

Group	Number of participant (n=85)	Mean age (SD) in year	Minimum – Maximum
Women	20	44.05 (8.6)	31 – 61
Girls	14	20.35 (3.7)	117 – 28
PLHIV	23	39.1 (11)	27 – 67
LBT	28	27.2 (9.4)	17 – 57

Table 4.1. Background Characteristics of participants

Variable	Women group (n=20)	Girls group (n=14)	PLHIV (n=23)	LBT (n=28)
Township				
Dedaye	0	0	9	0
Dagon Seikkan	6	8	0	0
East Dagon	14	6	0	0
Lashio	0	0	0	18
Tamwe/Thingangyun	0	0	12	0
Yangon	0	0	0	10
Education				
Primary school passed	7	3	7	0
Middle school passed	9	8	2	4
High school passed	3	3	7	9
University	0	0	2	6
Graduated	1	0	2	8
Missing	0	0	1	1
Marital status				
Single	1	7	3	23
Married	17	7	15	2
Widowed	2	0	2	0
Divorced	0	0	1	0
Missing	0	0	0	3
Occupation				
Government staff	3	0	0	0
Private jobs	8	4	8	10
NGOs	0	0	0	9
Peer Educator	0	0	0	3
Farmer	0	0	2	0
Odd jobs	1	0	3	0
Student	0	6	0	3
Dependent	8	4	8	0
Missing	0	0	0	3
Mean number of family members	5.2	4.7	4.5	4.9
(Range)	(2-10)	(2-12)	(1-8)	(1-10)

The background characteristics of participants from IDI were as followed.

Table 4.2. Background Characteristics of participants from IDI

Sr.	Age in Years	Sex	Education	Occupation	Marital Status	No. of family members	No. of children	Township	On ART
1	50	F	4th Standard	Hawker	Married	5	3	Tamwe	Yes
2	42	F	NA	Odds job	Married	4	2	Tamwe	NR
3	33	M	B.A (Law)	VCD rent	Married	3	NA	Thingangyun	Yes
4	30	F	1st yr (Physic)	Dependent	Married	3	Pregnant	Tamwe	Yes
5	37	F	2nd Standard	Hawker	Married	8	8	Dedaye	Yes
6	22	F	5th Standard	Odds job	Separated	5	1	Dedaye	Yes
7	50	M	4th Standard	Dependent	Divorced	NA	2	Dedaye	Yes

**NA = not available, NR = not relevant*

Annex IV –Story from a female sex worker (in-depth interview)

".....When I was young and first experienced working as a sex worker, I had some experience of being physically abused by the customers. Some of them were very rude and hit me to the face and nose. I was thrown into the water one time. I was working with one of the leaders of sex workers in our network. If the combination is 2 in 1, which means I was having sex with two men, the cost was 18,000 or 20,000 kyats. They let me go back home at about 4 am in the morning. Then the group leader gave me only 10,000 and he took 10,000 kyats.

I did this work because of my children. Before I worked as a sex worker, we could eat only one meal in a day. My children were very poor and looking for the dinner when other children were having dinner which I couldn't provide them. That's why I decided to work in the sex worker job whatever other people think of me. This is for my children.

Sometimes, I had to run when I met with a group of men and rude people. One experience was that I was followed by about 20 men at a traditional ceremony and I ran into the tattoo shop. I was thinking that it's better to get myself some pain from tattooing, rather than being physically abused by a group of men as a sex worker. Then I took a tattoo on me. .. ".