SUPPORT TEAM LEADERSHIP WORKSHOP REPORT

Hosted by SHAPE Zimbabwe Trust for volunteers from different organisations in Zimbabwe involved in care work and facilitated by Malcolm Marler, Director of The Support Team Network of the University of Alabama Birmingham in USA.

Held in Harare, Zimbabwe at Bronte Hotel, 24-25 April 2004

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Acknowledgements

This workshop was made possible through the magnanimity, benevolence and support of Pfizer and Park Nicollet Institute. On behalf of SHAPE Zimbabwe Trust, I extend my sincere gratitude to Pastor Malcolm Marler of The Support Team Network of the University of Alabama at Birmingham in the USA and our own staff for their effort, input and camaraderie. Many thanks go to partner organisations for forwarding their volunteers for this important training. We are grateful for their effort in recruiting volunteers for this workshop. In this regard we extend our thanks to:

1. Red Cross Society Zimbabwe
2. Goal Zimbabwe
3. The Centre
4. Young Men’s Christian Association,
5. Chiedza Home of Hope,
6. Hope Humana,
7. Chinhoyi University of Technology
8. Family Aids Caring Trust,
9. Zimbabwe Aids Network
10. Batsirai Home based care group
11. Makonde Christian Hospital
12. Karoi women’s Aids Network.
13. University of Zimbabwe SHAPE Orphanages project

In attendance, I acknowledge the presence of Professor Paul Terry from Park Nicollet, Minnesota, The SHAPE Zimbabwe Trust Directors, Shepstone Musiyarira and Tsitsi Beatrice Masvaure for radiating warmth throughout the workshop.
Introduction

This was the first time in Zimbabwe that persons involved in volunteer work have come together for training in support team leadership and volunteerism and indeed the first time that the concept and discourse of support teams have been discussed, learnt and made subject of training in Zimbabwe and Africa.

Volunteers from a plethora of organisations and eclectic backgrounds converged in Harare for this training on Saturday and Sunday, 24-25 April 2004. SHAPE Zimbabwe Trust with the help of Professor Paul Terry from Park Nicollet Institute in Minnesota USA enlisted the services of Pastor Malcolm Marler from the University of Alabama at Birmingham in the USA to train volunteers in Zimbabwe who are involved in care and support of persons infected by HIV/AIDS.

As the statistics reveal that one in four Zimbabweans is HIV positive, the need for palliative care and other special needs remains a national challenge that calls for all stakeholders to play their part. Care of the sick by members of the community and openly talking about the pandemic at the very micro levels of society helps in the fight against fear and stigma.

Support teams assist communities to come to terms with the situation through acceptance, caring for neighbours who are infected thereby erasing stigma and mobilizing collective responsibility in societies. The Support Team Network provides an avenue for volunteers to exchange ideas and share experiences, it helps widen the circle of care with the ultimate aim of delivering support to everyone in need of it.

This training focused on the training of Support Team Leaders who will lead creation of support teams in their communities. As the symptoms of the disease begin to show in individuals, support teams come in to bring normalcy and stability in the lives of the individuals by doing what they can to help, when they can, in a coordinated way with a built in support system.

The Workshop

The workshop started on Saturday 24 April at 9:10 am and there were welcome remarks and introductions done by Professor Terry from Park Nicollet Institute in the USA. The literati concluded his welcome remarks by introducing the main facilitator Malcolm Marler from the University of Alabama at Birmingham, USA. Malcolm encouraged everyone to participate, as it's the best way of learning. Malcolm said he is a pastor but not a church pastor. All the members of his
church are HIV positive. How is this possible? Because his church is a HIV clinic based at the University of Alabama in America. He said that the mission of the support team workshop is to offer national training and a resource centre, development of volunteer support teams and it offers support to persons with HIV/AIDS or other health concerns.

Malcolm started his presentation with a tone that was pregnant with intellectual insight. He started by employing and deploying questioning items with the question, “What is your purpose of life?” And answers were; to enjoy life, to help those in need and to be loved.

Malcolm said that his purpose is to help communities in need. In his lifetime, he always has had people who created an extended family for him and his calling is to help make other people be able to do the same to those in need. The participants then introduced themselves and their organisations.

Organisations represented included, The Centre—an organisation for people living positively with HIV, Young Men’s Christian Association, Red Cross Zimbabwe, Chiedza Home of Hope, Goal Zimbabwe, Hope Humana, Chinhoyi University of Technology, Family Aids Caring Trust, Zimbabwe Aids Network, Batsirai Home based care group, Makonde Christian Hospital and Karoi women’s Aids Network. In care work, a support Team is a team of people who provide support and the person receiving the support is called the Support Team Friend.

After introductions, Tinashe Mundawarara, a projects Coordinator from SHAPE Zimbabwe Trust, explained what SHAPE is all about. He talked about their training programmes, edutainment projects, youth clubs and gender workshops.

After the session on SHAPE, Malcolm took over and talked about caring for a person with HIV/AIDS. He said it is a challenge as it involves;

1) Medical
2) Practical
3) Emotional and
4) Spiritual

How can we effectively organise volunteers to care about the people who have HIV/AIDS? The problems faced by people with HIV/AIDS are just the same whether it is in America or Zimbabwe. These problems include isolation, stigma, judgement, medical treatment, jobs, income and housing. Stigma and judgement come out of fear and trying to put other people down.
The role of the support team is to provide spiritual, emotional, and practical support. The Support Team members are encouraged to avoid direct financial and medical involvement with the support team friend (the person who needs care). Providing financial resources changes the relationship and medical care is beyond the skill of most team members.

Malcolm Marler then explained the steps they have undertaken in building community support. The pastor brought in a second principle that if we want to be good teachers we have to be good listeners. He said that they listened to stories of their patients and families. From this they then interviewed clergy, priests and rabbis about their experiences with persons living with HIV. Most reported little or no experience. And so Marler wondered, how can we get clergy and lay persons in congregations to hear the personal stories of persons living with HIV?

Soon a weekly educational programme began for the community at the clinic. He said that in America they have almost eliminated mother to child transmission because of the use of nevirapine. Most clergy don’t know that there are many people in their churches who are HIV positive. Malcolm explained that there is this misconception that it can’t happen in the church because we teach good morals, etc. We have to remove stigma and silence; it is until then that we can start making a difference.

After Tea Break, Malcolm again asked, “How are people’s attitude changed? Participants were put into groups of 4s to answer this question.

The answers included people are changed through education to remove the myths and misconceptions by use of workshops and seminars, personal experience, forming support groups to have comfort in numbers (i.e. encourage each other); status after being tested because counselling is at testing centres and this helps people to make informed decisions. Leaders have to talk about it openly and should be role models walking the talk. If we are going to encourage others to know his/her HIV status, we need to know what all of the emotions are in related to being tested. He challenged each one of us to be tested for HIV so that we can share that experience as we teach. We don’t have to reveal our status to everyone, but we do need to talk about what we were thinking and feeling about getting tested as an example to others. He then talked about his experience of getting tested.

The pastor shared his third principle called GRACE. GRACE is an acronym for: Giving Receiving AIDS Compassionate Education. There were three main
guidelines he shared that are necessary for attitudes and behaviour to change: Head, Heart, and Feet.

Head--should have correct HIV/AIDS information. Address fears, questions. Myths and misconceptions of HIV were also discussed e.g. mosquitoes spread AIDS, sleeping with a virgin cures HIV, kissing and hugging spreads AIDS.

Heart--move people’s hearts so that their attitudes can change. People need to hear the personal stories of persons who are HIV positive or who are affected by HIV who the recipients perceive are like them. Earlier, Malcolm had mentioned that he was going to give workshop participants an opportunity to share what it is like to live with HIV. A “safe space” was created by talking about confidentiality and everyone agreed not to share anyone’s name who spoke up. He assured everyone that he was not interested in how they became infected with HIV, but more in what it is like to live with HIV or to have a family member who has lived with HIV.

Malcolm then asked if there were any persons who have been tested and know they are HIV positive among the participants to share their stories. Two ladies raised their hands. He also demonstrated that one of the most important questions to ask is “how can I help?” rather than “how did you get infected?”

A lady, Suzanne (not real name), who was a participant at the workshop gave a life testimony. Her husband died of TB and her kid of pneumonia in 1994. She started to develop thrush. She went for an HIV test and came out positive. She tried to tell her mother but she refused to believe her saying the doctor had given her the wrong information. She then joined Living Hope which supports people living with AIDS. Now the mother accepts it and is supportive.

Linda (not her real name) tested positive in 1994. She said she had 4 miscarriages. It was a difficult time for her because she knew she was faithful. Later counselling sessions helped her. She resigned from her work because of fear. However now she is a trained counsellor and she is so much into it. She now uses condoms when having sex with her husband and their children know about their status.

Another woman raised her hand and talked about what it is like to have a sister who is HIV positive.

The disclosure by the participants was the highlight of the day and most people in the workshop felt touched by the narrations and this session helped people to understand and know that there are people out there who are ready to talk openly about their status. It also emphasized that “people like us” are affected by this disease.
It's important to tell your own story about HIV/AIDS to remove stigma. The word grace means love which is unconditional so we have to love others especially in need (those who are positive, they really need our love).

The Pastor then went on to talk about building support teams in the communities. The first phase is Beginning and Building and this involves invitation to team members and recipients, and preparing a team through orientation. Connecting, Caring and Sustaining, involves setting realistic expectations for everyone, coordinating the work of the team and sustaining that team. This according to Malcolm should be underpinned and disciplined by the together principle. The together principle states that; “Do what you can, when you can, in a coordinated way and with a built in support system. Thus the team process that begins with **Beginning (discovery), Building (orientation), Connecting (setting expectations), Caring (organising and doing), and Sustaining (keeping the team healthy).**

In the afternoon session, the participants discussed the question, What is a Volunteer? Answers that came include; a volunteer is someone ready to be used in a positive way, someone who enjoys doing something so much that they are prepared to do it without being paid, someone willing to do something for free. In coordinating volunteers there is need for motivation, they need to be treated with dignity and respect.

The participants were then divided into groups for a team building exercise and Malcolm asked anyone from their team to take anything from their pocket and put it on the table and then to list the different ways this item could be used. He encouraged us to think outside the box, not just the obvious ways. The exercise proved the importance of team work. Compared to individual work, team work gives everyone opportunity to share ideas, unifies people, is more fun and energy and gets ideas going.

Malcolm employed the green bean casserole rule. The rule emanates from a story that tells of Malcolm’s visit to a support team friend. One day Malcolm visited a support team friend called Mike and Mike asked Malcolm to tell the support team that was visiting him not to bring green bean casserole to him and Malcolm asked why? Mike said that he didn’t like it and every time he received it he would thank the team members, throw it away after they had gone because he would not want to hurt their feelings. The main premise of the green bean casserole rule is that one may love to do something or to offer something, but we always want to ask the Support Team Friend or Family if they would like to receive it. It’s a respect of persons. It applies to everything the team does, not just cooking.
Marler asserted that a support team works well when there is good coordination, good leadership, understanding the mission, one spirit among team members, rules and guidelines give you structure and members need to complement each other’s strength.

In the support team, doing what you can means do what you enjoy instead of doing everything. Volunteers should be asked what they like doing and this gives them motivation. Doing these things when you can means that the task should not be repeated over and over again by one person. Doing things in a coordinated way means that there is need for a coordinator to make sure that what is needed is provided. The coordinator makes sure what needs to be done is done at the right time.

Participants were divided into groups and asked to think of persons who are sick and list things they need. Things brought forward include; love and support, care, compassion, entertainment, medical treatment. Malcolm then presented and explored with participants on what is emotional support and spiritual support.

He took the participants through an exercise where each participant tore 16 pieces of paper and write four activities they enjoy, four things they are thankful for, four people who are important to them who are presently living and four roles they presently play in their lives. The participants were told to place the slips of paper face up, choose one out of each category that they must lose, tear it up, put it off to the side. He then asked the participants what they were thinking and what their feelings as they made their choices were. How is this like the experience of persons we may be caring for? Again he asked participants to turn the papers over so that they cannot see what is written on them and asked them to choose one role, one activity, one person, and one thing they are thankful for without looking at what they had written on them, tear the papers and put them away. He asked again, “How is this like the experience of persons we may be caring for?”

Malcolm taught the participants that they need to “Walk at the same pace emotionally as the person you are supporting.” The pastor gave an example of his father who walked slowly and he had to take him shopping and along the way had to contend with his step and move at the same speed with him. He said this can be difficult but one needs to have patience. The pastor then employed and deployed his allegorical lexical items by playing the role of a chronic illness in the room. He asked people to keep quiet and observe their feeling from the proceedings he moved around the room taking all of the slips of paper from one person, pretending to take other people’s slips, touching them
but not taking them, taking from others. He asked participants whether this was easier than the last exercises and how they felt when their slips where taken and when they had none taken from them. He concluded the exercise by telling those people who had slips taken away from them that it was only paper and that they still have all those things.

How is this like the experience of persons we may be caring for? He finished by saying that we need to take on the role of student in our relationship with the Support Team Friend, and allow him or her to teach us what this experience is like for him or her.

In summary this exercise taught us what it is like for persons living with HIV and three ways we can offer emotional and spiritual support: 1) Help a person feel what he or she is feeling as they are feeling it. We can do this by simply asking an extra question when we hear a feeling being shared to better understand what it is like for them. 2) Learn to walk at the same emotional pace as the person we are helping. Don’t try to change or fix the feeling, but walk beside people without judgement. 3) Take on the role of student with your support team friend and learn from them, rather than trying to provide all of the answers.

**Support team Workshop- Second Day Sunday 25 April**

This day was categorically less hectic than the first day. Participants were more relaxed and were enjoying themselves. They all seemed won over by Malcolm’s gentle wit and great artistry of presentation and facilitation that kept all attentive and eager to learn. The day began with a joke from Professor Paul Terry and then a recap of the first day that was well punctuated with mnemonic hints from Malcolm. Malcolm was glad that participants had been able to remember all things he had taught from the previous day.

Malcolm reiterated that this was a training for trainers. Support Team Orientation’s second component was “Helping People Understand the Support Team Model.” The three components for Orientation for new teams included providing emotional support, understanding the support team model and setting healthy boundaries and limits. Importance of confidentiality, time consciousness was asserted. Lack of confidentiality may tear the team apart. There is also need for an open door policy where members are free to join the team but communication can become a challenge when the team gets bigger. The leader of the team should be one who loves to organise, help coordinate schedule of team members, loves to delegate and be experienced in chairing meetings.
After this session there was a Tea Break and a group photo.

After the Tea Break participants were divided into 5 groups and were asked on issues of boundaries that are there in the support team at individual level and as a group. Issues that arose include; paying medical fees, financial support, personal gift giving, emotional support, taking advantage of support team friends, payout religion and confidentiality.

We need to respect people’s wishes as team members (e.g. some people may not want others to know that they are HIV positive).

Support Team members should be committed to the team concept and aspects of confidentiality. Confidentiality within the team means not keeping individual secrets and team friend but sharing important information within the team. Confidentiality means not sharing issues outside the team.

The group went for lunch and upon return there was group work on meetings. The groups were tasked to come up with characteristics of a bad meeting. Examples forwarded include; No agenda for the meeting, unnecessary argument, too long, leaving agenda, no refreshments.

Participants then learned how to run an effective meeting with a simple outline: communicate, educate, and coordinate. Communicate means share what it has been like for you in visiting with the support team friend in the past month. Learn from each other’s experience. Educate means the team needs to learn something new together each month to improve the care. Keep this simple and relevant. Coordinate means have a team calendar and know what each other are doing in the coming month to maximize everyone’s time and skills.

The SHAPE Zimbabwe Director Mr Shepstone Musiyaria visited the workshop and gave a brief address to the participants, thanking them for their attendance.

The final component of support team development, Sustaining, was discussed by the participants as they were divided into groups based on their organisations and locations and were asked to come up with a way to move forward following the workshop.

Suggestions that came up include; communicating through e-mail with other workshop participants, Tsitsi and Tinashe were to organise a follow up workshop, have at least one meeting per year on support teams, and Malcolm pledged to seek funding for support team network workshops for Zimbabwe and Zambia.
Participants at this stage were equipped with the necessary skills to form support teams in their communities and widen the horizons of care by getting more and more people involved through initiating support teams. The together principle (Doing what you can, when you can in a coordinated way with a built in support system) was reiterated as the key to sustainability and operations of support teams.

Malcolm concluded by thanking the participants for their amazing contributions and inputs during the two days. Three participants gave a vote of thanks and the SHAPE projects coordinator, Mr Tinasehe Mundawarara thanked the participants for their participation and hinted that this was a landmark event and a harbinger of great things to come in the care of the infected persons in our communities.

The workshop enabled participants to discover what they like to do and also discover the needs of the people they want to care for. Team members should also be flexible, that is, decide what they can do month to month and communicate it to their team members. A support team cannot do everything that a person needs but they can do some.

Evaluation of the workshop by participants had 100% of the participants saying that the workshop was very effective. A majority of the participants were impressed by Malcolm’s presentation skills and all of the participants said that they had learnt something new from the workshop. Topics highlighted by participants include the together principle, building support teams and changing attitudes and the Head, Heart, Feet principles. One participant commented that “the workshop was an eye opener, I feel privileged to have been given the opportunity to attend the workshop.” Asked on what they did not like about the workshop, all participants said nothing except for one who said too much food. They all commended SHAPE Zimbabwe Trust and Malcolm for a job well done.