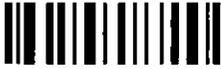


standing together

an interview
with

Winnie Chikafumbwa



The following interview took place in Lilongwe in August 1996, within the weekly meeting of the National Association for People with HIV and AIDS in Malawi (NAPHAM). It began with the singing of welcoming songs. Throughout the conversation Winnie Chikafumbwa spoke in English and her words were translated into Chichewa to ensure the participation of all who were present.

NAPHAM was formed in 1993. There were four of us: three positive women and one man. At that time, the main problems that we wanted to address were those facing widows and other women. In Malawi, when a husband dies, it is common for the relatives of the deceased to come and take away all the property, leaving the woman with nothing to support her children or herself. Sometimes if the husband's only property is a house, then the wife is chased away and the relatives claim her home. The situation is often similar for women when they are diagnosed as HIV positive. It is common for women to be diagnosed first, as often the first detection occurs after a pregnancy screening. When these women go back home and break

the news to their husbands they are often chased away from their homes or alternatively the men sometimes desert them. Women in these circumstances were becoming destitute and had nowhere to go for support. We decided to form a group so that we could give each other support and empower each other. It was very important for us. It was important for us to hear each other's problems and to try to voice our needs and experiences.

We knew that when speaking out alone our voices could not be heard. We hoped that if there were two, three, four of us joined together maybe it could change things. The courage came from the first four people who started it. We became very strong. We spoke out and gradually other people joined us. We didn't have any funds at first so we were meeting under a tree. NAPHAM was actually formed under a tree here in Lilongwe. We had no idea of how to get funds, or where to go for help, until a certain diplomat who had seen the four of us meeting every Sunday under the tree became very interested. He asked us what we were doing and, when we told him, he offered us a space to meet in his house. He also assisted us in contacting people and securing assistance. The group was officially formed, we elected a committee, and opened a bank account to facilitate our meetings. This was a little over three years ago.

At first we thought that if we began to speak out we would be discriminated against, but it didn't happen that way. Discrimination happened to those who kept quiet.

Even now, those who are quiet are facing discrimination, but those of us who are out in the open are not facing these problems. We are speaking out, telling the truth so no-one is suspecting or gossiping about us. If you keep quiet it allows people to start pointing the finger at you and it really hurts. Even your health can deteriorate because you isolate yourself, you are afraid to go out and instead remain indoors thinking about it.

Generally we are being accepted and supported by the community. Sometimes we think that we will be discriminated against, or we will be rejected by the community, but we are finding that if we talk about it, if we tell our neighbours, we start it ourselves, we take the power away from gossip. Of course there are still instances where people are rejected by their families for saying they are HIV Positive, but this is becoming less common. It is ironic that sometimes people are so surprised at your honesty that when you speak out and tell people that you are HIV positive they don't believe you.

When we started the group, the main purpose was to encourage each other to live a positive life with HIV. To do that we meet here together on Saturdays for spiritual counselling and then we share with each other the daily problems that we are facing and try to identify how we can solve them. We talk about both individual problems and organisational problems.

We also go out into the fields to teach in the community and

encourage those who are still hiding to come out. When we go into the community and give our testimony, people become curious. They wonder how we can speak out in public, how we can have the courage to do so. People might not feel free to disclose in public, but we give out our address and later we find that they come and see us. We counsel them and they go for a test, or perhaps they already know their status. When we go out into the communities we also try to teach the people how they can prevent discrimination, how they can help to care for those who are sick in their community, and how to prevent becoming ill themselves. We go out into the villages, churches, workplaces, schools, markets and beer halls. We do it as a group. Everybody has got to get involved. We share the jobs. Four go one time, then another four, then another four. The other work we do is home-based care. In towns like Lilongwe there are no community care groups. We were aware of a need for home-based care, especially for some of the women who had been rejected by their families. We decided that we needed to start caring for each other, so we started home-based care.

We are trying to establish our own income generating activity but that has not happened yet. We have many ideas. We have submitted many proposals and we are still waiting to hear if they will be supported. Most of what we have done we have done on our own. We haven't been able to go to training but we are using our personal experience. We have learnt

management and administration skills through making mistakes. We do everything on our own.

We are proud that we have this space and that other people are now giving us funds for office rent and to pay the wages of a few members who are themselves living with AIDS. But most of our work is voluntary, including the home-based care. Members are given transport money to get home but that is all.

There have been other people who have tried to destroy our organisation. Last year we were in a very difficult situation. People were going to the donors and telling lies about us and nobody was paying us any attention. But we are very united. We started this group on our own. We know our problems and no-one is going to stop us, no-one is going to separate us. We kept on fighting and said we are not moving an inch. And when people saw this they were amazed. They were shocked at our courage, and people started coming back. This year we are so happy that we have received funds to conduct outreach activities and buy books. We know that we are moving and becoming stronger. Now we have an office and eleven paid staff. That is an achievement to us!

Our organisation is mostly made up of women, but at some meetings the numbers of men and women are balanced. We are united as men and women. It is not difficult to work together. We are just like brother and sister. We have a common problem. We have never really quarrelled because we are doing this

together. We haven't separated the work roles. Usually in African culture it is the women who are supposed to go out and care for the sick, but in this group we say: 'No way. Who is going to care for you when you are sick?' So we do everything together. In home-based care either one woman and two men, or two women and one man, go and care for the patient. It is the same with outreach services. We don't send only men to go and teach somewhere - men and women go together. We have a united working relationship.

Recently we have been demanding that we should be included at any meeting that concerns AIDS. We are stating that they shouldn't hold a meeting in our absence, because in those meetings they are discussing us and our lives. We don't want them speaking for us or making decisions in our absence. We are demanding that each time we must be there.

The members are very supportive and united. It can be difficult, the community can reject you and the government often doesn't listen. But if we are united, if we are four, five, six or ten, and we write about our problems, if we sit down together in a group and speak out, then people start wondering, they start changing. I know it is difficult, but we have to start it ourselves.