

# **PART TWO**

## *ORGANISING TAC TO BUILD A BETTER HEALTH SYSTEM*

# 8. NATIONAL ORGANISERS REPORT BY MANDLA MAJOLA

## **REPORT FOR THE NATIONAL EXECUTIVE COMMITTEE MEMBERS**

In the last few months I've been fortunate enough to work in four different provinces, that is Western Cape, Kwazulu Natal, Mpumalanga and Gauteng Provinces. It has been an experience to see the strength and weakness of different provincial offices, especially the civil disobedience and after civil disobedience.

Though I was requested to lead some provinces in civil disobedience but my major assignment was to set up TAC structures or assist in strengthening the existing TAC structures in these different provinces. The commitment of these provincial offices in ensuring that we have fully functioning structures is exceptional and the enthusiasm of our country volunteers in taking TAC campaigns to their communities through branches is very encouraging.

The level of commitment of different provincial offices and the enthusiasm of our volunteers can be measured by the impact of our civil disobedience and the success of our march in Cape Town on the 14<sup>th</sup> February 2003. Firstly the march in Cape Town was well organised and the success can be attributed in the TAC nationally i.e. our provincial offices especially the Western Cape provincial office in terms of mobilising and the national office for giving the necessary technical support to make the march successful. On that day we all witnessed different racial groups, religions, or cultures coming together to say we had enough, please provided treatment. Unfortunately we all know that didn't happen, hence we opted for civil disobedience.

Once again mobilising and organising civil disobedience wasn't easy because of the controversy that was associated with the concept of civil disobedience, but most important because our key allies distanced themselves from our campaign and some movements divorced, but nevertheless all departments in TAC, i.e. nationally, provincially and locally carried out civil disobedience with a great deal of discipline and diligence. In both events there is a room for improvement, but at least we should feel proud and pleased to have leaders and volunteers who are committed to the cause.

### **Treatment Action Campaign Structure:**

In terms of structures, most of the TAC provinces e.g. E.C and KZN have adopted a strategy of building TAC in the provinces by starting branches in different communities. Both Gauteng and Mpumalanga provinces also joined the other provinces in starting branches.

The idea of having these branches is to ensure that we increase TAC membership, but most important we carry out TAC programmes within our own communities, this includes education awareness, health survey and network with other movements.

The uniform approach of structure that proposed is to have branches and have regional committees, where branch reps from different surrounding communities met at least forth nightly, and finally have PEC i.e. where branches are represented and are meeting properly once a month. In different provinces we have temporarily put in place an organising committee that carries the responsibility of maintaining the branches in terms of programmes and help the branches to implement these programmes. We have also developed in different provinces and inter-grated approach between the organising committee and the treatment literacy facilitator with an idea of building branches that are informed and knowledgeable issues. As our profile is growing higher everyday, so will be our challenges. These are some of the challenges that I think needs urgent attention in order to improve the functioning of the movement, and most of these challenges I've picked up in my visit from different provinces.

### **Challenge**

The ability to administrate in our provincial offices needs to be improved. The level of political understanding in these different provinces and provincial offices is worrying. Encouraging our provincial offices to focus on programmes not only events. Ensure that we have uniform strategy in terms of structures in TAC.

### **Solution (Proposed)**

Intensive training for our administrators and office staff

Implement the idea of political leadership school, but it should include the provincial staff members. Deploy national staff members in different provinces to help the provincial staff members to develop proper programmes.

Co-ordinators should take full responsibility for the functioning of TAC structures.

Staff to conduct evaluation of our staff members, nationally so as to help us to improve our weakness.

## **MANDLA MAJOLA'S ASSESMENT OF THE WESTERN CAPE**

This office looks better than most of TAC provincial offices in terms of provincial programmes and staff co-operation. The good thing is that the space that is created for volunteers to emerge and make meaningful contributions to the movement. The challenge of the co-ordinator is to be confident in delegating responsibilities more often to these volunteers.

### **Administration**

This department remains one of our shortcomings as a movement and it will affect the operation of TAC structures in the long run. The problem with our administration department is not confined only in the western cape but is a national challenge. For example inviting organizations to any TAC event or meeting remains an uphill battle. Our administrators need intensive training to ensure that our provincial offices are working smoothly.

### **TAC Structure**

TAC is growing very fast in this province. The reason emanates from the fact that we have been able to touch different sectors of our communities and the impact of educational programmes i.e. Project Ulwazi. There are 45 branches who are selected based on their activism, knowledge, and commitment and good leadership qualities. The purpose of the structure to monitor the branches and help them to develop branch programmes and ensure that disputes amongst the branch members are resolved peacefully. And to help give political direction in the branches. Integrated approach with the treatment literacy and organizing committee helps to strengthen the TAC branches.

### **Relationship with other Sectors**

The forum that was established for the march 9 14 Feb 2003) where many NGO's / CBO's attended should be revived by WC Provincial office. The purpose of this forum should be to exchange programmes with other movements and ensure that TAC's agenda is not dissented.

Organising such a forum in all provinces once a month will help to make TAC a stronger movement nationally.

### **The Challenges of the Western Cape**

Integrate other groups of colour in TAC Western Cape.

Establish general meetings to exchange programmes with other movements.

Sustain TAC branches and structures in the Province.

## **MANDLA MAJOLA'S ASSESMENT OF GAUTENG**

I spent a week in Gauteng with the purpose of assisting provincial office to develop the branches in the province, like in most TAC provincial offices we have committed comrades / staff members but the challenge is that they are not trained enough to back their mobilizing / organising strategies with good administration skills. This is one area that is affecting our performance including the role of a provincial co-ordinator. Again we need to develop systems in this provincial office that help to make our work much easier. In order for TAC to have proper functioning structures we need to ensure that we have efficient provincial offices with staff members who have a clear programme of action.

The Gauteng office is fortunate to have an experienced co-ordinator and the support of some of the NEC members in their province but I think the challenge would be to ensure that the Gauteng office create a space for volunteers to take responsibilities and to train them in order to take up leadership positions within the province.

### **The structures**

The Province has done well in terms of mobilizing people and to TAC events but the challenge is to create branched where those members are going to affiliate and continuously participate in TAC programmes. In essence we need to

consolidate our membership and equip our membership with relevant information and knowledge – this means our branches should be center of knowledge and strength for ordinary community members. In Gauteng we must build marriages between our events and our programmes so as to have a community based movement.

As an attempt to create branches from different areas / region Gauteng Staff, and myself agreed that it will be proper if we invite key volunteers from these regions to a meeting and explaining to them the structures that we envisage in Gauteng and how to form them and what programmes we expect from the branches.

The meeting was well organised, most of the key volunteers attended and we explained to them the vision of province and the idea to start proper branches where TAC members meet regularly. The response from the participants was excellent and they went on to raise problems that they normally encounter in their own different communities. One hopes that we will build on this and the visits that the office I am going to explain this idea further. It is only through branch systems that we are going to have educated, disciplined and competent cadres. It is only through branches system that we are going to rectifying the misconception that and its structured constructed about TAC and its agenda and politics around HIV/AIDS. It is only through branch system that we are going to create HIV/AIDS competent communities

### **TAC & Other Structures**

Gauteng offices has done better than other offices in terms of networking with other movements but there is still a need for the office to have general meetings for all the sectors where they are going to be briefed about the issues.

## **MANDLA MAJOLA'S ASSESMENT OF KZN**

The report will cover the states of:

Branches  
Treatment Literacy Committee  
Support Groups  
Provincial Events

The total numbers of branches in the Province are 26 and two new areas where TAC branches have not launched, those areas are:

Indwedwe  
Port Shepston

The existence and the consolidation of membership have been determined by the provincial events are the provincial office has not yet paid enough attention in developing programs with branches. This has remained a challenge for the KZN provincial office.

### **Events**

In the period of four months from January to May 2003, the provincial office has embarked on five successful events.

On the 20 March 2003, Civil Disobedience took place at C.R. Swart Police Station, three hundred and forty seven (347) TAC volunteers signed forms for civil disobedience and more than 200 participated on the 20<sup>th</sup> of March 2003.

On the 31<sup>st</sup> March 2003, we marched to CR Swart Police Station as a result of unacceptable treatment we got from the police force on the 20<sup>th</sup> of March 2003, which has resulted to the assault of our discipline comrades.

On the 17<sup>th</sup> April 2003 the provincial leadership comprise of local leaders and PEC went to CR Swart Police Station to get a respond on memorandum was handed over to superintendent Jacob in regard to the charges of two national ministers (Dr Mantombazana Msimang and Minister Alec Erwin)

On the 17 April 2003, the community day of action went successfully in more that twenty branches except Clerment. Pamphlets and posters were distributed and presentations were conducted in different community.

On the 6<sup>th</sup> & 7<sup>th</sup> May 2003, the health community day of action went well in co-operation with doctors in different hospitals and clinics.

## **MTCT Support Groups**

The increasing number of support groups has not been doing well. So far we only have two MTCT support groups that are based at Eddington Hospital and Poly Clinic. That has resulted to the low pace for MTCT monitoring in public hospitals. Workshop on MTCT monitoring committee is required in order to empower MTCT committee which has not been functioning.

## **Treatment Literacy Work**

The province has a treatment Literacy Committee, which has a task to conduct workshops in different sectors including branches. The T.L Committee consists of ten TAC volunteers. From January to May less has been done. Two workshops have been planned to equip committee members, one of them failed miserably to take place as a result of improper planning.

The National office together with the Provincial office is working on solving problems that TL co-ordinator has come across.

## **Challenges**

The following are the challenges to be overcome by the provincial office as part of TAC strategies.

We have to ensure the functioning of the organising committee in order to assist in developing branch programmes.

We have to ensure the functioning of the Treatment Literacy committee in order to be able to disseminate information on treatment literacy and the distribution of material.

We have to make sure that the Provincial Executive Committee is functioning not only theoretically,

Improvement of the leadership and management skills to the staff members.

Establishment of the relationship between TAC and scientists in the Province.

## **Regional Office**

One of the achievements we have in the province is the opening of the new regional office in Pietermaritzburg. It has 30 support groups and 10 TAC branches. Detailed report about funding on that has been forwarded to the management committee.

# **MANDLA MAJOLA'S ASSESMENT OF MPUMALANGA PROVINCE**

## **Introduction**

Mpumalanga province is a very wide province with many communities scattered across the province and mostly dominated by rural and semi-urban communities like Eastern Cape and KZN. It is estimated that there is an HIV/AIDS prevalence rate of 18 – 19 % and the level of understanding HIV/AIDS from the people are still very poor. Tswana, Zulu, Ndebele and North Sotho mostly dominate the province.

TAC in this province operates from Nelspruit with only one staff member Themba Shabangu as Provincial organiser. In spite of many difficulties, she is doing very well.

## **Administration**

There is no employed administrator but there are volunteers who are helpful to Themba, for the office to function properly we need to think of providing a stipend to one volunteer who will assist Themba with running of the office when she is doing the groundwork. There is one volunteer she has managed to identify who will assist her with administration and I think this will help to offload some responsibilities from her shoulders.

## **Programmes**

There are no proper programmes only an instant reaction forms the call of the national office. We have agreed with Themba that:

The focus on the next few months will be to form and develop branches from the five different communities that are closer to Nelspruit, because we've got many volunteers who are participating in TAC from those communities. We will invite presentations from different NGOs e.g. Grip, Ndlovu Medical Centre and other people like doctors, nurses and social workers, every Wednesday whether on ARV's/MTCT or OI's any topic that will uplift the level of understanding of our volunteers and also will strengthen our working relations with different people and NGOs in their province.

## **Structure**

There is no TAC structure for example branches but we are having five different communities like Barberton, Likazi and other communities who have quite a good number of TAC volunteers. We had two intense workshops attended by 30 volunteers from five different communities. The workshop was to explain the concept of branches, how to start a branch and what role does it play and which programme they should focus on as branch leaders or branch members. On the second workshop they came back with reports and informed us about the days if they would choose as different branches, their venue and issues they explained to people. On the second workshop it was clear that we were making progress and that they were also very confident and clear about the way forward.

On the second workshop we selected two members per branch to form an organizing committee / PEC. The purpose is to meet fortnightly and give reports back about their branch meetings, to develop programmes, share experiences and exchange ideas on how to make a branch effective and to come up with strategies of recruiting new members.

For the composition of this structure we agreed that we would also include the representation of different support groups so as to draw more people living with HIV into TAC, also reps from different NGOs. Once a month we will have general meetings where many NGOs, CBO's, labour movements and other sectors will be invited to learn more about TAC's programmes and to allow exchange of ideas. We also hope that this will strengthen the idea of networking.

We have also built a relationship with the Ndlovu medical center run by Dr Hug Tempelman. It is located in Elandsdoorn Township, Mpumalanga Province. We agreed on a working relationship but unfortunately we don't have a strong TAC presence in that area. The medical center offered us an office and a computer for branch members to use. I shared some ideas with Thembane on how to make TAC strong there and I think we should seize opportunity because it will help build a strong TAC.

# 9. ORGANISING FOR TREATMENT: TAC OVER THE NEXT TWO YEARS: 2003—2005

As TAC completes the first phase of our civil disobedience campaign, it is a very good time to reflect on our strategy and tactics over the next two years. How can we ensure that people get medicines and how can we ensure that there is a decent public health system for all people?

All TAC volunteers/members and supporters believe in the rights to life, dignity, equality, freedom, health care access, social security access and social justice. These are principles we cannot compromise.

TAC has succeeded because we understand that HIV/AIDS is a political issue. But we know HIV/AIDS is not a party political issue because it affects all people. HIV/AIDS is political because of inequality. Prevention, treatment and care remain hampered by social and political inequalities at every level of society. Gender inequality, poverty, migrant labour and sexual taboos produce vulnerability to HIV within our communities. Personal, family, local community, provincial, national and international relations all affect whether we have access to prevention, care, treatment and how we are exposed to the risks of HIV transmission. We see the need for HIV prevention and treatment as an essential part of the struggle to ensure human rights, security, gender equality and social justice.

TAC has succeeded because we rely on science as our best ally. We do not have the truth. We seek the truth through good science, medicine and expertise. In using good science and good faith, TAC does not leave decisions to experts but we educate ourselves in the best scientific traditions to understand medicines and society. We rely on rigorous research and base ourselves on real facts and experience.

Treatment and scientific literacy have become TAC watchwords. We communicate in every way possible – songs, emails, newspapers, videos, televisions, newsletters, leaflets and posters. TAC does this because many of our members cannot read, many are educated but do not understand science or health policy. We must reach everyone in society – urban or rural, rich or poor, black or white. We create our own media and we use every media outlet to get our message across – local newspapers, TV, radio (community, regional and national stations). As the comrades in KwaZulu-Natal say: “Knowledge is a public asset”

TAC is proud of our democracy, our tradition of struggle, our Constitution and our democratic institutions. We have educated our members about the Medicines Control Council (MCC) and the importance of the scientific and independent regulation of medicines. The role of patents, globalisation, compulsory licences, multinational corporations, the World Trade Organisation (WTO) and access to medicines remains an ongoing education process for all TAC activists and leaders. Many people in our country learnt about profiteering and patent abuse when TAC illegally imported fluconazole from Thailand. TAC members gave the legal concept *amicus curiae* (friend of the court) widespread currency when we fought the multinational drug companies alongside the South African government. We won this battle because we educated ourselves and our members on the need for international solidarity – across the globe people joined our battle. Our members and broader South Africa learnt that our Constitution and the courts have a real meaning for poor people when we challenged government in the MTCT case and won. Parliament and its committees are not strange to ordinary TAC members. We have marched to parliament, we have picketed parliament, we have given evidence to Parliament, we support good legislation and we criticize shoddy laws. TAC members try to understand the budget. We learnt about the Medical Research Council and the Human Rights Commission. TAC gave the word NEDLAC meaning to many people who are not members of unions or business organisations. Many ordinary people in our country had not heard about the Competition Commission until TAC used it together with Cosatu, CEPPAWU and many allies to expose excessive prices by multinational drug companies.

Many of our members and broader society learnt the need to work together through TAC – we work with anyone who believes in the right to life, dignity, equality, freedom and access to health care.

TAC has organised marches with tens of thousands of people throughout our country. We have come to the point of civil disobedience because of the government's denial, foot-dragging, deliberate misrepresentation and allowing unnecessary deaths. Where has this strength come from?

Our strength comes from nearly 10 000 ordinary people living with and affected by HIV/AIDS who identify as TAC volunteers or members. Most are poor. Many, many have HIV/AIDS. The majority are women but we have many young men who are willing to learn and change. Some are wealthy. Some have education. All of us have seen people die. We watch as their CD4 count declines and the HIV viral load explodes. All of us give our time, energy, love, anger, privilege and patience to the cause of preventing a holocaust against the poor.

Our strength comes from our branches, provincial and national leaders. It also comes from working with other sectors: unions, faith-based organisations, lesbian and gay groups and many others have supported TAC campaigns. Now is the time to ask how can we create a social movement that will ensure a decent public health service for all people and a serious HIV/AIDS treatment plan. TAC branch development, treatment literacy programmes and our constitutional rights are the only tools we have at our disposal for this task. We must build a TAC branch and treatment literacy programme in every health care district in the country. This will strengthen primary health care delivery, assist in local development and ensure access to a range of social services other than health.

If government signs the Treatment and Prevention Plan and begins to provide ARVs, we will need such a force to help health workers and people with HIV/AIDS. If government does not sign such a programme, we will need a force that will challenge it at every level and also ensure that we access resources to provide treatment. This means orienting all TAC forces to the development of branches in every health district in the country. It means assisting existing branches with better education, treatment literacy, activist skills and resources.

At the moment TAC has more than 110 branches in Eastern Cape, Free State (pending), Gauteng, KwaZulu-Natal, Limpopo, Mpumalanga and Western Cape. We also provide support to very large numbers of HIV/AIDS support groups. Branches vary in strength and in leadership quality. Sometimes provincial leaders (staff and NEC members) see the power and potential of our branches, other times we see it as a burden.

Our entire national apparatus must be organised to realise the potential of strong branches in every health district.

## **WHAT DO BRANCHES DO?**

In various ways, all branches have at least eight identifiable and inter-related functions: Education (Treatment Literacy and Political Education); Public awareness and mobilisation; Local Network building; Health Service support and monitoring; Creating and developing support groups; Lobbying with MPs, councils and other institutions at local level; Supporting development and social security campaigns.

## **EDUCATION**

Education is the first and most important function of a branch. Knowledge is one of the most important benefits any TAC member/volunteer receives. We learn about medicines; about TAC history; about the science and the political economy of HIV and many other issues. TAC branch education takes two forms: (a) Internal education that combines political education about HIV/AIDS and treatment literacy. (b) Public treatment literacy work is provided to community groups, religious organisations, trade unions at local level. We also learn about the law, the enforcement of rights and good gov-

ernance. TAC's national and provincial treatment literacy co-ordinators provide the human and material resources for this work.

Every branch must develop an internal and external education plan with their treatment literacy co-ordinator. Treatment literacy must be integrated with organising work and the building of TAC.

### **PUBLIC AWARENESS, LOCAL MEDIA AND MOBILISATION**

Branches distribute material (and condoms) at taxi ranks, shopping centers and clinics. Branches paint murals and conduct door-to-door visits. This raises public awareness on treatment issues and the role of TAC. Branch leaders work with local media such as community radio stations, newsletters and drama groups. We also use video, organize marches, petitions and support provincial and national mobilization. Youth, schools, clinics, clubs, shebeens, shopping centers, churches, mosques, synagogues and temples are vital to developing public awareness on HIV/AIDS treatment and prevention.

Every TAC branch must have a serious mobilization strategy. We must recruit new members, volunteers and supporters. Every member and branch must write for and distribute *Equal Treatment*, the TAC newsletter

### **LOCAL NETWORK BUILDING**

Many TAC branches have good working relationships with other community-based organisations. We work together. There are children's organisations, women's groups, religious youth groups, AIDS organisations, development organisations and many other bodies. We must have a plan to visit and educate all organisations. TAC branches must support at least one event sponsored by a local ally or organisation every month. For instance, if a local children's organisation organises an event to promote children's health, we must ensure that the whole branch supports it as if it was a TAC event. But, we must not take over other people's work.

Every TAC branch must have a list of local organisations. We must visit them regularly based on a branch work-plan. TAC branches must ensure that local organisations have information about our campaigns and that they participate regularly in treatment literacy work.

### **HEALTH SERVICE SUPPORT AND MONITORING**

Our clinics are over-worked. Sometimes, they have too few nurses, no medicines, phones that do not work and many other problems. This demoralises health care workers and people who use the clinics. TAC members and volunteers must change this. Every branch must adopt at least one clinic. At the moment TAC is organising a clinic survey. This is to ensure that TAC members know what is available in their clinics. TAC members must also help their clinics get the staff, budget, information, medicines and training that it needs to serve the local community. Provincial co-ordinators must learn about and explain the district health system to all branches. In this way, we must ensure that clinics and hospitals serve the interest of all people in our communities. Later in the year TAC will organise provincial meetings of nurses, doctors and other health workers in the public sector to join hands in campaigning for better health care for all.

### **SUPPORTING SUPPORT GROUPS**

Many support groups are active in TAC. We support the work of many support groups. Why? There are many personal, social, emotional, legal and health problems that individuals with HIV/AIDS face. It is our job to ensure that every support group has the tools that it needs to do this job. We must make sure that support groups become centers of strength for people living with HIV/AIDS. Every branch must have a list of support groups or where there are no support groups, branches must start support groups. TAC branches must compile a list of good doctors; bad doctors; clinics; pharmacies; good religious leaders; children's organisations; paralegals and other **local and provincial agencies** that can assist the work of support groups.

## **POLITICAL LOBBYING**

Every councilor, MP (provincial and national) who has an office in your branch area must be visited. Priority must be given to the ANC because it is the party that rules the country and has the power to change things. But, all political parties must be lobbied. Make sure they understand TAC and they know about HIV/AIDS treatment and care. Ask them to help monitor health services and to ensure that the needs of poor people and poor communities are always a priority.

## **SOCIAL JUSTICE CAMPAIGNS**

As an organization, TAC supports every effort to end poverty, to create jobs, to improve health, housing, education, water and transport for all people. TAC is affiliated to campaigns to improve the grant system. We support the extension of the child support grant to all children under 18 and the abolition of the means test. We also support the campaign for a basic income grant (BIG). TAC branches must be actively engaged in campaigns for social and food security for all people.

## **THE ROAD FORWARD**

All branch infrastructure must be strengthened. How can branches get access to computers and other information? Every TAC branch needs the following:

- A good meeting place
- A book for minutes
- A book to maintain TAC accounts
- A membership list and membership forms for new members
- A place to store all TAC materials that members need for their daily work
- Lists of all local organisations, support groups, religious leaders and groups, councilors, clinics, hospitals, pharmacies, schools and other bodies to network with and to keep informed of TAC activities and campaigns.
- A record book that keeps a list and report of all events (workshops; pickets)
- A list with the contact details of all TAC provincial and national offices

Every branch must discuss this document and send a list of suggestions on how to build branches to Zackie Achmat and Mandla Majola. We also need ideas for a code of conduct for members and office-bearers.

# 10. TREATMENT LITERACY EDUCATION- What Branches can do

**Please read this document together with the “Organising For Treatment Document” produced to assist TAC branches to strengthen work in their districts.**

Since its inception, TAC has struggled in different ways to make treatment available to those who will die without it. We know that about 200 000 people died in our country in 2002 due to AIDS related infections. There are many reasons people die of AIDS related illnesses: it can be because (1) they or those caring for them do not know that HIV Opportunistic Infections can be treated, (2) they know that OIs can be treated but do not have access to the medicines as they are not available at clinics or hospitals, (3) they do not know about antiretrovirals that can prolong life of people living with HIV or (4) they know of antiretrovirals but cannot afford them.

TAC has tried to address some of these problems by advocating for a National Treatment Plan. But TAC has not only asked government to implement this plan and waited. We have already started implementing aspects of it including: going to clinics and hospitals to make sure that the medicines needed by people living with HIV are available, educating people living with HIV, their carers and communities about their rights and the treatments themselves so that they know what to ask for when they go to clinics. We do this education through our Treatment Literacy programme.

One of the big problems is that many health care workers have just seen people with HIV die and for them HIV/AIDS is a disease people die from and not one which people can live with for long. Therefore, when activists say people must be given treatment some health care workers and people in charge of our health care system think we are misleading people or are trying to cause trouble.

This continues to be a problem of many in our government. As a result, we see our government, especially health departments, spending a lot of money on home based care and not on ensuring that our clinics have regular supplies of medicines or that health care workers are trained to diagnose illnesses and treat them accordingly or that communities are educated about HIV treatments and how they work so that people do not die from illnesses that can be treated with medicines that are available.

As we move towards the co-ordinated and collective implementation of a National Treatment and Prevention Plan, our responsibility as people living with HIV/AIDS, those caring for us, Priests and Bishops, Teachers and Students, community members, government departments, workplaces and especially TAC activists becomes more difficult and easier at the same time.

Our task is difficult because we must now all learn about: the science of HIV, how our bodies are made and how they work, the immune and other systems, the relationship between our bodies and germs that can make us ill, how medicines work - their benefits, side effects and limitations, antiretroviral therapy, the potential benefits and limitations of “alternative or herbal home remedies” many of us have grown to trust, etc. For long we have been able to rely on doctors, nurses, scientists and others to take charge of our health. But HIV puts a new challenge on all of us. We have to take charge of our own health; we have to become experts in HIV/AIDS and how we can use medicines to improve our health. With Medicines like antiretrovirals, the nurse or the doctor are an important part but just one part of what is needed to make them work. For medicines to be effective, we have to know how and how not to take them, with what kinds of foods or other medicines, what short and long term effects the medicines have, what to do to prevent side effects and how to manage them when they do occur.

Our biggest job is ahead of us. To do this we will need lots of support. Our communities need to be educated and mobilised to be ready to give this support when South Africa starts implementing a national treatment and prevention plan that includes antiretrovirals.

## **HOW AND WHERE DO WE LEARN ABOUT ALL THESE THINGS?**

The Treatment Action Campaign has produced a lot of materials that can be used by people without much medical background.

### *POSTERS*

**A set of 7 posters dealing with HIV Opportunistic Infections** has been developed and should soon

be available at all TAC offices in English, Xhosa, Zulu, Sotho, Tswana, Afrikaans, Venda, Isonga and Sepedi. These must be put up at all clinics, hospitals, schools, taxi ranks and other places where people can see them.

**An information poster on antiretrovirals.** This one is available in English for now and will be translated into other languages. Your branch can take the initiative to translate it into a language mostly spoken in your area and ask the National office to print copies for you in your preferred language.

**An information poster on preventing Mother To Child Transmission of HIV.** Available in English, Xhosa, Zulu and Afrikaans

To put posters up, if you do not have wall paper glue, you can make a runny mixture of the white flour we use for bread, smear it all over the back of the poster and paste it on a wall. Try not to use Prestik as it dries up quickly and the posters will not stick for long. As a branch, you can turn this into an activity and invite willing community members to help you. This way you get your community involved in your work as a branch and you can attract more members. You can plan to cover all the places you choose over a month and have a special day every week where you cover an area and finish it. As we put up the posters, we must tell people who are watching what we are putting up and invite them to come and read. It can help to put contact details for your local branch neatly written on the poster or on a visible piece of paper next to the poster.

Ask your Provincial office for other materials you can put up in your community in this way.

**If there is a support group in your area make sure that they have copies of all these posters and discuss them with members of the support group.**

**You can also make your own posters about an issue you feel your community needs to know about. You do not have to wait for the national office to do this.**

## **HIV IN OUR LIVES: A BOOK OF INFOSHEETS ON HIV/AIDS**

TAC, together with the AIDS Law Project, has developed a book of information sheets dealing with many different aspects HIV/AIDS. It is called ***HIV IN OUR LIVES*** and will soon be available from all TAC offices and branches. This book is developed for use by all those interested in learning about HIV/AIDS, especially people living with HIV in support groups. It is in English at the moment. When money becomes available, we will translate and print it in different languages. However, in the meantime, your branch can translate the infosheet you want to use and discuss it with your members. The idea is that TAC branches, doctors, nurses in clinics and hospitals and other organisations will make photocopies of single infosheets and make them available to patients who come to clinics and hospitals. Anyone can do the same in their church, school, etc.

## **YOUR DOCTORS, NURSES, COUNSELLORS ARE YOUR ASSETS**

Although TAC takes responsibility for educating its members through structured training workshops and discussion sessions, we do not have capacity to reach all our branches at the same time. But all our members must know these things if we are going to campaign effectively for the services to be implemented where we are. Therefore, even though not all Nurses, Doctors and Counsellors have accurate information about HIV/AIDS and treatment, some do have the information or know someone who does and we must ask them to help us. You can make a list of all doctors in your area whether they work in private practices or in local public clinics or hospitals.

**Make a list of all the things you want to know about HIV/AIDS and treatment.** Introduce yourselves to the doctor, nurse or counsellor as a TAC branch and ask them to help you with training where they can. Tell them about the things you do in your community and that you do your work for free. This will encourage them to help you and show you where you can get extra assistance.

If the doctor, nurse or counsellor does not know something, contact your Provincial or National office to assist them to find the information you need.

You can have a schedule of days when you want to do workshops.

# HOW DO WE DO TREATMENT EDUCATION IN OUR COMMUNITY?

The posters and visual materials will help a lot, but you can do many other things as well.

## *Use visual materials - Treatment Access Poster Series*

A series of exhibition posters with stories and photographs of people living with HIV or fighting for access to medicines for people living with HIV was developed with a photographer called Gideon Mendel. This is a very useful tool we can use in branches for education at public places. We can ask our local library, museum, clinic, hospital, school or community hall for space to exhibit the posters and have a table with all other TAC materials and registration forms for others who want to join TAC. We can run this as an exhibition going for a week or few days combined with ongoing education as groups come in and out. Each branch can translate these stories into a local language and print them on a piece of paper put next to the relevant posters for those who cannot read English. Other branches have made tape recordings of the stories and play them for those who cannot read but can see the pictures.

## *Show Videos and facilitate discussion*

Community Health Media Trust has produced a series of Treatment Literacy Videos dealing with different aspects of HIV and HIV treatments. All TAC offices have copies of these and a branch can borrow a set for viewing by members or for a public activity where they show the videos to the community. During your Community Health Day of Action you can ask your local clinics or hospital or another organisation for a video machine and show these to the public. The public can ask questions and you can answer these as a branch. You can also invite doctors and nurses for these days to help you answer questions. Do not be afraid if you cannot answer a question, admit that you do not know everything and that you will find an answer and come back to the person asking.

An organisation called “**Steps to the future**” has also developed videos on HIV/AIDS that you can use. Ask your TAC office where you can get these.

## *Make a song about an issue*

TAC activists have made many songs about HIV illnesses, HIV treatments, Testing for HIV, using condoms, using our rights to ensure better services, etc. In many communities, music has a special place. It is the one medium all people can relate to and we must use it to assist our work. For people who cannot read, a song can be very effective to teach about an issue. Songs are also good because all age groups can relate to them. Once you have discussed an issue as a branch, you can make different songs to simplify the messages and scientific concepts.

An example is the song TAC activists sing about preventing Mother To Child Transmission of HIV. It goes:

***AZT siyayazi, ikhusela bantwana kwiHIV, jikekele  
Nevirapine siyayazi, ikhusela bantwana kwiHIV, jikekele  
MTCT Prevention, MTCT Prevention***

*(we know AZT and Nevirapine can protect children from HIV, MTCT prevention, everywhere)*

You can sing these songs at clinics, schools, taxi ranks as you do education to complement your presentations. They are good because you can easily teach to the whole group and the whole group can become involved in your education. People remember songs more than words.

You can make your own book of songs as a branch and even record these for your branch. If there is a local radio station, you can ask them for a short slot and play these songs now and then as part of your mass education.

You can decide to have a community health day every second week of the month where you march around wearing your HIV positive T-shirts, carrying posters, distributing condoms and singing your songs. Remember to distribute a short pamphlet with contact details for your local branch when doing these. The community will remember the messages in your songs and will join your march because the songs attract them.

### *Make a drama and act it out for the community*

Short dramas can help a lot to make things clear for people and help communities see a different picture of something. Dramas are one of the ways in which many communities communicate to each other. You can take the community's experiences and highlight them for the community to reflect on through a drama. For example, if there is a problem with stigma and discrimination of people living with HIV in your community you can make a drama that shows one example of this and then also show how and why this is wrong and give an alternative way of responding through your drama.

As another example you can show someone who is diagnosed HIV positive, does not know that HIV opportunistic infections can be treated and thinks he or she will die. Then show through your drama that if he or she goes for treatment as soon as he or she becomes ill, he or she will not die unnecessarily. You can do the same to publicise services like social grants and highlight other problems like women abuse if it is a problem in your community.

There are also other forms of drama that involve the community in shaping the responses called Forum theatre. In this form of drama, you come as a group with a situation. You act it out and then you invite members from the audience to come and act how they would do things differently or solve the problem presented in the short drama. As many people as possible from the audience can come to show their views and as the group facilitating this you can drive things to the desired conclusion. In many communities, there are people who have gone to school to learn how to do drama so again you can work with these people to help you make your dramas as good as possible. This way you can develop relationships with many people in your community and maybe they can also join your TAC branch.

### *Create a library for your branch*

In your branch, you can have a person specifically responsible for education activities. This person must start a library of reference materials on topics on or related to HIV/AIDS. You can start by keeping two sets of all the materials TAC, the AIDS Law Project, Department of Health, Soul City or other organisation has produced and a register of who takes what out when. The branch education officer can then make sure that at every meeting one person reads something new and gives a short input before or after the other agenda items of the meeting. Many TAC branches have started what they call "**UMRABULO**" which is a series of education discussions where old and new TAC activists come and educate each other on key topics of HIV/AIDS and related things. This can be once every week or fortnightly. We can invite experts from universities or other organisations, as well as our parliamentary constituency office or doctors and nurses to help us discuss a certain topic, e.g. social grants that already exist such as the disability grant or child support grant or grants that we are campaigning for such as the basic income grant. But we can also find documents on the topics and give responsibility to a branch member to read the document and explain to the others. All members can take turns to do this and this will help develop a culture of reading in our group. The topics we discuss do not have to be on HIV alone or social grants alone. People can also take a good novel like "**Things fall apart**" by **Chinua Achebe**, read it and explain what is happening in the book and what lessons we can learn from it for our community. Remember HIV is related to other things that happen in our society and that the main function of a TAC branch is to build a new society. We must therefore also discuss other things that affect our community. But understanding treatment is our primary responsibility and challenge now, so we must read as much as possible on HIV and HIV treatment.

We can all learn about HIV treatments, science, legal concepts, economics, etc and we have the opportunity now. By learning about these things we can beat HIV together.

Government must lead us by signing the **Nedlac Framework for a National Treatment and Prevention Plan** and by adopting a **policy to use antiretrovirals in the public sector**. This will help guide all of us and get rid of the confusion and uncertainty. This will help us as TAC branches and communities to do the work we already do even better - and save lives.

We must prepare the ground for HIV treatment to work now by educating ourselves and everyone else in our community about these treatments. Then once it is started, it will be more successful.

For further assistance with doing treatment education in your community you can call the Treatment

Literacy co-ordinator at the following TAC office numbers:

<b>National office:</b>	021 788 3507	(Sipho Mthathi)
<b>Gauteng:</b>	011 339 8421	(Johanna Ncala)
<b>Kwa Zulu Natal:</b>	031 304 3673	( Bongiwe Mkhutyukelwa)
<b>Eastern Cape:</b>	043 760 0050	(Linda Mafu)
<b>Western Cape:</b>	021 364 5489	(Nomfundo Dubula or Vuyiseka Dubula)

## 11. Treatment Literacy: Jan – May 2003

### *What the programme tries to achieve in 2003?*

- Broadened understanding of HIV Prevention and Treatment by the general public. *This is done through training workshops, radio programmes, posters and other visual materials put up at key public places including clinics and hospitals, schools, churches, community centres.*
- Preparing communities for treatment through focused HIV treatment education programs at clinics (MOUs, TB, HIV dedicated clinics), support groups of people living with HIV and schools and building of other HIV/ AIDS service organizations capacity to do treatment education
- Using Treatment Education as a foundation for building TAC branches  
Strengthening of treatment activism by training key activists on treatment issues who can train others.
- Development of and popularizing treatment education materials beyond TAC volunteers

### *Overview*

There are 2 main elements for the programme in 2003. The one is to develop focused treatment education interventions that are tailor-made for specific sectors. Examples are Western Cape's Project Ulwazi's:

- Clinics users education programme, where trained TAC volunteer educators visit key health care institutions offering HIV targeted and related services on a daily basis and educate patients in waiting rooms.
- The PLWA training programme, where TAC volunteer educators conduct treatment education in support groups with the aim of turning support groups into learning institutions for people living with HIV.

Linked to development of focused treatment education interventions, the other core area of the programme's work this year is the **development of appropriate training materials** (See section on materials development).

The other thread is to popularize treatment education by building capacity of HIV/AIDS service organizations, CBOs, NGOs and others, Health care workers (including Counselors, Home-based carers, community health workers) to do education use TAC education materials and develop their own materials for educating the communities they serve.

### *Opportunities*

- **Nationally, organisations have begun to realize the potential of strategies that integrate prevention and treatment in dealing with HIV.** TAC has gone furthest in developing both the thinking and materials dealing with these issues in an integrated fashion. Thus, there is a lot of demand on TAC staff and volunteers to assist different organizations and institutions.

- **Treatment Programmes mushrooming throughout the country**

There are currently ??? pilot treatment programmes that have been set up in the country. Despite the neat designs of these programmes, not many of them are directly serving the purpose of mobilising and preparing communities for treatment. Many of them are research projects and do not have a well- developed community mobilization component. Since the HAART meeting, many programmes have recognized the importance of community mobilization and have approached TAC for assistance.

We have supported where we can, but there is an urgent need for us to write our model as it can serve to advise future planning for treatment programmes and in fact for a national treatment programme. There are currently no

community-oriented models for treatment education in SA, TAC has pioneered this aspect and we need to document it. I want to propose that NEC approves our proposal to appoint a writer for our education programmes throughout the country. This will help us to develop our model further and modify as is required and to use our work politically.

• **International demand on TAC to provide a model/ models:**

Since the establishment of PATAM and the ITP Summit in Cape Town where discussions centered on treatment advocacy and treatment education, our materials have become popular worldwide. We are currently supplying in electronic and hard copy version, Zambia, Zimbabwe, Malawi, Namibia, Botswana Ghana, Cameroon, Togo and other countries with our treatment literacy materials.

The writing up of our education programmes has become even more critical for treatment access in Africa and other developing countries. Just as the world has learnt to expect leadership from TAC through its advocacy work, the world is expecting us to provide a model for effective community education and mobilization on HIV/AIDS.

## *Key activities*

### *Materials development and distribution*

#### *Posters:*

• **7 posters dealing with HIV Opportunistic Infections have been developed.** These are being used for training on opportunistic Infections and are being distributed through TAC offices, Clinics, Life Lines, ATTICS and other AIDS service organizations in different provinces.

• **ARV poster**

These have now all been translated into 8 other South African Languages (Xhosa, Zulu, Suthu, Tswana, Afrikaans, Venda, Tsonga and Sepedi) and are currently being printed.

5000 each of these were printed and so far, about 4000 have been distributed to clinics, Hospitals, AIDS service and other organizations in all 9 province. We have used the ATICS, Lifelines, community advice offices, support groups and CBOs as distribution points. The posters have been received very well in general but there is demand for other languages.

#### *Booklets, other education support materials:*

- MTCT (booklet and Flipchart used for education workshops)
- OI guidelines booklet
- AIDS know the facts
- Clinicians Society ARV Guidelines for Adults. The ARV Guidelines for Children are currently being prepared for printing.

Thousands of all these booklets have been distributed. We are trying to set up a method to systematically distribution to broaden access to these beyond the areas surrounding the TAC offices. There is a desperate need to broaden access to our materials to all districts and not just the districts where the TAC offices are. To deal with this, we have set up a distribution list nationally, with input from provinces, so that materials can go from the printers to all distribution centers in different parts of the provinces. We have also started to send our materials to government departments.

Western Cape has agreed to assist in distributing the OI posters to all its public hospitals and clinics.

In Eastern Cape, we are doing it through districts and it is promising. This seems to be an easier root but there is still need to get the province to recognize the materials and endorse that they be put up for clinic users education.

### *Treatment Manual (EMPOWA)*

For the past few months, a large degree of effort has gone into developing a Treatment Manual that should assist treatment education at different levels.

#### *Structure:*

The manual is structured into four booklets, each containing about 10 chapters ( $\pm$  100 pages). Initially, the plan was to have 6 different booklets but it was decided to merge 2 with the rest.

- \* Book 1: Deals with health, politics, learning and teaching
- \* Book 2: Mother To child Transmission (science and social issues)
- \* Book3: HIV virology and Antiretroviral therapy
- \* Book 4: HIV associated illnesses (Opportunistic Infections) and management

***So far:***

A book of 27 information sheets, which is part of the manual, has been completed. It goes for printing next week. These will also be translated into selected SA languages.

Revisions from comments that have been forwarded have been done on all the booklets, these are available for further comment on CD and hard copies.

***Time frames:***

It is planned that all comments and further development be completed in the next couple of weeks. After this, putting the material of Book 1 into form ready for layout should begin by first week of June.

This will help set the frame for the others and from there things should go quicker. Realistically, it is estimated that layout and all DTP work should take at least another 2 months, for all the books. Attempts will be made to fast track the process but end of July is an ambitious target for getting all this done. All will depend on completion of text.

## ***2. Building Treatment Literacy and capacity of AIDS service organizations to do treatment education***

As part of the plan for this year, each province has a targeted number of trainers to be selected from support groups and other HIV/AIDS service organizations from identified districts. This group will be trained over the year and supported by the respective TAC offices to start treatment education in their areas and organisations.

***Course Format:***

A series of 5-10 day intensive training workshops, each of 30 people at a time. A standard core curriculum has now been completed. District networks of trainers comprising of Medical professionals, TAC activists who have been trained and individuals of proven reputation are used to facilitate these training workshops.

A process of application and screening of participants before the training workshops begin is applied. Participants must prove that they will use what they gain from the training beyond the workshops. The training courses are advertised through TAC networks with organizations in the area and direct contacting of people by TAC office.

## ***Provincial activity***

### ***1. Eastern Cape***

In 2003, Treatment Literacy has taken off in the province and has become the driving force of our work. The Treatment Literacy Co-ordinator works in an integrated fashion with the organiser, so that both areas of work reinforce each other.

**Through Treatment Literacy, we have been able to achieve the following:**

- Strengthening of existing branches
- Establishing a core of confident volunteers who can train others and assist in mobilising in the province. These volunteers are working in clinics, schools and support groups.
- Build strong networks with various organisations, especially those who did not take treatment seriously before.
- Built strong relationships with healthcare workers at different levels
- Identify gaps within the health care system and needs of people living with HIV and health service providers

## ***Activities: January - February***

We have trained 35 volunteers from the 20-24 January 2003. This was used as a process of selecting potential volunteer educators. We had interviews and selected 16 volunteers. This process was concluded on the 17 February 2003.

We also visited 20 existing branches and with the branch members selected 3 members per branch to serve as branch educators. On the 24-28 we trained 60 branch educators.

## ***MARCH***

In March, we started work in the Amatole District targeting municipal clinics in the district. We targeted 18 clinics, 18 villages and we managed to reach 15 clinics and a hospital. We also worked with all the 18 communities where the clinics are located. These included:

- Grey hospital
- Sweet-waters
- Ginsberg
- Phakamisa
- Zwelitsha zone 2, 5 & 8
- Tshatshu
- Mdange
- Tyutyu
- Peelton
- Zanempilo
- Jafta
- Peerie
- Mdingi
- Dimbaza
- Mahleke

***We have managed to get 7 communities to form branches.***

- Ilitha
- Ginsberg
- Ndileka
- Godidi
- Mt coke
- Tolofiyeni
- Zone 4.

The communities consequently formed HEALTH ACTION TEAMS and we set May 5th –7th for training of these branches.

## ***APRIL***

We then moved to **NKONKOBÉ MUNICIPALITY**. There are 54 villages. We worked with 9 communities and Fort Hare. Contact person for that area is Ms Piet. She has continued to organise in schools, faith based organisations and villages. There are 4 clinics servicing 54 villages. The Mxhelo village has a mobile clinic that comes once a month that means there's no condom distribution. She has agreed to distribute condoms for the 4 neighbouring villages; we left 2 boxes of condoms and introduced her to Fort Hare VCT Site. We will be training a core of community Health forum stakeholders in June the date to be confirmed. It will be happening in Fort Hare. Mrs Piet has continued to get condoms from clinic for distribution

## ***NGQUSHWA MUNICIPALITY***

We worked in Nqgushwa municipality from 07 – 11 May 2003

We met with Peddie women support centre, Nasoda, Peddie advice office, Ngqushwa municipality, PPASA and village chiefs. There are 112 villages

## ***INTERVENTION STRATEGY***

- Train representatives from each organisation.
- Train community Health forum that is active & also an affiliate of Nasoda.
- Train existing pool of volunteers in the area to provide workshop
- Work in schools and faith based organisations
- Workshop Contralesa members in the area for intervention in Circumcision

***We have reached the following schools:***

- Qetho
- Marheledwane
- Mfundo
- Fundani
- Nathaniel Pamla
- Mpheko
- Pikoli
- Siyathemba
- Prudo
- Masixole
- Mzoxolo

***We also worked in the following health care institutions***

- Nompumelo Hospital
- Marheledwane
- Ntshamanzi
- Mgwalana

***Villages reached***

- Mgwalana
- Kwagwalana
- Marheledwane
- Qetho
- Mazizini
- Ntshamanzi a combination of 4 villages
- Prudo
- Pikoli.

In the villages issues of condom distribution in schools were raised. Parents were concerned that the department of education was distributing a policy of no condoms in schools. They wanted condom education in schools as part of life skills. We met with Mrs Gwarube who is the Provincial co-ordinator of the Life orientation program in the Eastern Cape. She re-enforced that their policy is Abstinence. We discussed the issues with her asking her to do reality check on youth sexuality. She then agreed that they are providing insufficient information. We are now in partnership with their program and have since given them poster for distribution in schools. They have agreed that NGOs should work with them in schools and provide condom education. This meant that they have to change their policies we are monitoring that

We worked in two municipalities Mnquma and Mbashe. From the 12 May to 15 May 2003. We covered Butterworth and surrounding villages, Idutywa and surrounding villages, Centani and surrounding villages. On the 12 and 13. We had 26 participants from the following organisations. Child welfare, Women Support group, support groups, Faith based organisations and youth. We had community members from Tsomo, Nqgamakwe and Stutterheim.

We were hosted by Women support Centre and Thembalesizwe as well as Municipality. On the 14 and 15 we worked in Idutywa and Centane. We were hosted by Idutywa HIV/AIDS care and information Centre. We had 30 participants from different support groups, Social services and faith-based organisation.

We focussed on Opportunistic Infection; Sexually transmitted infections and their treatment, Healthy living and nutrition. The group raised issues like unavailability of treatment in clinics. Most people in the group about 17 of them either had thrush or other opportunistic infections AND THEY WERE NOT TREATED.

They also raised issues on grant problem. Their district surgeon is not very supportive infect he is down right stupid. People who have a CD4 COUNT of 97 and lesser are not recommended for grants. We are planning on action on this issue as it is affecting both municipalities. Diflucan is sold at R35 per pill and Acyclovir at R4. 49c per pill and they are not available in clinics.

***Treatment literacy training for other organisations:***

We have trained 51 participants from student partnership worldwide This strategic partnership is working in Nqgushwa and in Umtata. They are now working in different villages and are training people in treatment literacy. We trained 18 participants from DPSA national reps as a spin off. We were invited to train regional reps this will happen in July

We trained 30 Home based carers sponsored by Portnet. We trained Health Advisory committees in Bisho municipality. After holding mini workshop in clinics, clinic committees were formed. We had 45 participants. Our way forward is to

get Diflucan in clinics. We also worked with 30 participants from different Support groups. They were from Reeston, NU1, NU3, NU12, Postdam, Empilisweni, Masizakhe, and Joy for Hope and Masikhule. We are currently developing a list of Eastern Cape Support-groups; we have 40 at the moment.

We trained them on the following Treatment literacy, Advocacy and role we play in mobilising communities as support groups. Each support group was given a set of posters and Equal treatment as well as treatment plan. The next module will be in June on social security.

### ***Distribution of posters, other materials and Equal treatment***

With the posters, we work shopped branch educators and support group members on how to use these as tools for education and Community mobilisation. Each branch was given 3 sets. Each support group was given 2 sets of posters. We also gave each volunteer educator a set to use in their training programs 25 clinics were given sets. The department of education was given 20 sets.

Cosatu King Williams Town was given 20 sets and we have given sets to all the people and institutions we have worked with in the different districts and regions.

### ***WHAT IS IN OUR TRAINING PROGRAM***

- HIV Virology and immune system
- Epidemiology in SA and in the Eastern Cape
- Opportunistic Infections, and their treatment.
- PMTCT
- Human physiology and how HIV affects the human body
- Sexuality, Sexually transmitted Infections and their treatments
- Antiretrovirals
- Politics around drug licensing and how this affects us
- Treatment plan as a mobilising tool
- How to organise workshops
- Community entry processes and building TAC branches
- How to effectively take up campaigns in our communities to improve services

### ***Staff development***

This is an area we need to pay more attention to. We have participated in several training workshops by other organisations, e.g. we attended a training on nutrition and HIV. We also attended a training on HIV/AIDS and the law, by AIDS Legal Network.

## ***Challenges***

### ***Organisationally:***

- TAC has grown tremendously in the province and is becoming recognised by many organisations. While we cannot meet all the demands of the Eastern Cape community, there is a need for satellite offices in other areas. Also, the work we are doing in different districts requires follow up.
- There are many volunteers involved in our work. Supervising them is a challenge.
- Branch education remains a challenge. We set up a system of branch educators but monitoring and motivating them is difficult, especially because we also work a lot outside East London.
- We need a car, our feet are sore and it is very tiring to take TAXI from village to village and hiring a car all the time is expensive.

### ***Lusikisiki:***

In Lusikisiki, an organizer has been contracted for 3 months to set up TAC branches in the district and surrounding areas. A team of 8 volunteers has been trained and has started going to schools, and will rotate in the 13 Lusikisiki district clinics being serviced by MSF to do education and assist the MSF counselors to train support group participants. A broader programme of treatment literacy for the community is being designed.

## ***2. Western Cape***

Project Ulwazi has become a very respectable aspect of TAC work. It is recognised by provincial Health authorities and the Education Department in the province has invited us to develop a programme integrating treatment and prevention that they can adopt for schools throughout the province. Our challenge therefore is to write our model and to define the different elements in a way that our work can be replicated. There is also huge demand on TAC by NGOs, Faith Based Organisations, AIDS service organisations, Workplaces and schools for Project Ulwazi to conduct workshops for them as we specialize in HIV treatments and well known for advocacy. We have trained 50 Support groups around Western Cape; we have also formed, through Project Ulwazi, Aids Action Committees in 16 schools. Project Ulwazi has also done workshops for health care workers, teachers and has organized conferences for People Living with HIV/AIDS.

### ***January - February:***

This time was spent setting up the programme; identifying strategic places that treatment literacy work will target this year and selecting volunteer educators.

### ***March***

In March the formal work started and we are now working in 6 schools, 10 clinics (2 TB, 4 HIV dedicated, 2 MTCT and 2 and with the support groups linked to these clinics.

### ***April: Learner's Conference***

The conference took place in Lutheran Youth Centre in Athlone on the 2nd –4th April. It was attended by 80 learners from 20 schools around the Metropole and Overberg regions.

### ***Aims of the conference***

- Strengthening of existing Aids Action Committees (AACs) and formation of new ones in schools beyond the 15 that already have AACs to support learners and educators with HIV/Aids and drive schools programmes.
- Strengthening of the existing AAC and help to develop programmes of action e.g. condom distribution, HIV/Aids Policy and formation of support groups for learners and teachers with HIV/Aids.
- Incorporating AAC into TAC Youth sector and take up campaigns for treatments.
- To promote openness and explain available services for learners with HIV/Aids.

### ***All the learners reported the following key challenges in their schools:***

- No Lifeskills education and no systematic HIV/AIDS education
- Unavailability and inaccessibility of condoms
- No HIV/Aids policies in their schools
- No support groups for learners and teachers with HIV/Aids.

Project Ulwazi will follow up with the schools, the teachers and learners will organise meetings with SRCs, and School governing bodies to workout programmes for the schools.

### ***THERE IS A NEED TO DEVELOP YOUTH FRIENDLY MATERIALS THAT THE TAC CAN DISTRIBUTE.***

### ***Building capacity of other organisations for treatment education:***

So far, two 5 day training workshops have been conducted:

- Unicity Training: 45 trainers from support groups, AIDS service organisations and other organizations
- Southern Cape, an initial 5-day workshop, which turned out to be bigger than expected (80 participants), has been conducted and will be followed up by smaller, more intensive ones.

In the Southern Cape workshop, many people voiced frustrations and anger about lack of access to treatment, bad health services. They appreciated the training a lot and a committee was set up to build a TAC branch there and take up the cam-

paings we identified during the training.

The health care workers who participated were very happy with our visibility and they raised issues of bad working conditions and they are prepared to join the TAC health workers campaign. There are no support groups in the areas and many people do not know about treatments. The nurses also complained that they had been waiting to be trained but the training never gets there, it always ends at the level of the Metropole. Sister Rutsa a Personnel in Thembalethu clinic said that she supports TAC and she is furious with our Government's response on HIV/Aids. They all said they are tired of looking after people only so that they can help they die. The health workers there all said that if TAC resumes Civil Disobedience Campaign they are prepared to be arrested.

Our next training workshop will be in the Knysna area in the first week of June. We plan to have covered all districts of the Western Cape by September.

### **3. KZN:**

KZN has 1 Metro (Ethekwini), 10 district municipalities, and 50 local municipalities. Since the beginning of the year, work has focussed on building a core of treatment literate activists and to set up a programme that targets Clinics, Hospitals, Support groups of people living with HIV, Schools and HIV/AIDS service organisations. There is now a team of 10 volunteer educators who have started working in the sectors explained above, including workplaces.

Work with other organisations has begun and there is a 5 days training programme planned for beginning of June. KZN is Targeting 200 people from other organizations for training as trainers by end of the year.

Several workshops have been run for TAC activists and there is a weekly education programme called "Umrabulo" that has been set up for volunteer education support.

#### ***Difficulties:***

Difficulties remain the same, it is hard to get to places as places are so far apart and the office does not have transport. Staff often have to carry heavy materials they need for workshops from bus stops and Taxi ranks.

Like all other provinces, there is a need to define more the strategy for treatment literacy for this province.

### **4. Gauteng**

In Gauteng, 8 volunteers educators have been trained. They have also started educating in schools; clinics and some are working with Support Groups. Johanna has also been supporting the Mpumalanga office with treatment literacy activities.

The Treatment Literacy co-ordinator has also made presentations for various organisations. On 25-27 March, a Youth Leadership workshop for peer educators from 12 different high schools in the kathorus area (i.e. katlehong,thokoza and voslorus) with aim of forming sustainable school aids committees.

A lot of work needs to be done to develop the programme here and to identify opportunities. In doing this, the Treatment Literacy co-coordinator in Gauteng can benefit from the assistance of people who know the province well.

#### ***Key things for treatment literacy from here on:***

- Writing our model(s) for treatment education and for use in Lobbying of key institutions, organizations and government to start systematic treatment education programmes
- Getting SAQA approval of our education courses
- Establishing of treatment education demonstration sites in each province. This will be done by selecting 1 or two key TAC branches in each province and strengthening its capacity to do treatment education at community level
- Formalizing a Healthcare worker training programme, working with MSF
- Strengthening capacity of HIV/ AIDS service organizations to do treatment education.
- Popularising our materials by establishing a systematic distribution process

# *12. TAC Youth Report by Arthur Jokweni, TAC NEC Youth Sector Representative*

The youth of today have to face up to the real fear of dying young as more and more young people in South Africa become infected with HIV and AIDS.

South Africa became a shining example of democracy to the world after the struggle against apartheid was won. But today it faces a new struggle against the challenge posed by the AIDS epidemic. The commitment and dedication of the young people in the 70s and 80s is an example to the youth of today to take control of our future.

Today we salute the heroes who paved the way for us to have better lives, but we must now take up the fight on behalf of those like Nkosi Johnson and the many other young people who have been lost to us through AIDS.

The Treatment Action Campaign (TAC) has taken the important step of offering the youth the opportunity to mobilize and join in the struggle to fight this epidemic that has claimed so many young lives. It is an epidemic that threatens the future of our country and we need to empower ourselves to work towards an AIDS-free society.

## ***Youth task teams***

In order to mobilize and get the youth involved, youth task teams have been formed in various provinces. The aim of these teams is to:

- Introduce the youth to the TAC and to programmes relating to HIV/AIDS;
- Initiate programmes for schools, other institutions of learning and youth organizations;
- Form AIDS action committees at schools for students and teachers.

These teams coordinate the youth committees and report back on their plans and what is going on in their provinces. This helps head office to check what support is needed and share experiences in mobilizing with other provinces.

## ***How do these teams do this?***

- Planning activities within education and other institutions and forming action committees of young people;
- Engaging the youth through holding youth forums and meetings to which all provincial youth organizations in their provinces are invited. Here they are informed about the TAC's programmes and other relevant issues and told about future activities.

## ***The task teams so far***

There are already task teams in Gauteng, Western Cape, Eastern Cape and KwaZulu . In Limpopo and Mpumalanga there are people who are working on building teams in these provinces, Oupa, Sis Buyi, Thembani. There is a need for support in these areas to get more young people in these provinces involved.

## ***Support and improvement***

This project has been a big challenge to all those who have been involved in forming these teams, but with more support we can win the struggle. The support of all the co coordinators has been amazing and most encouraging, but more is needed, especially from the national office if we are to meet our goal of saving young people's lives.

## ***Challenges facing us in future organizing***

- To organize the youth has been a challenge in that we needed to identify committed people who would engage other youth in their communities.
- It has been a big challenge to support each other in the provinces to build these team and their programmes.
- Implementation of programmes.

***Following are activities that have been planned and implemented by the teams in the various provinces:***

<b>Province</b>	<b>Activities</b>
KwaZulu Natal	<ul style="list-style-type: none"> <li>•Meetings with different youth organizations</li> <li>•A youth workshop held in the city hall</li> <li>•School visits to Inanda PR school, Emandlethu High and school around Stanger</li> <li>•School debates at Itselimnyama in Marianhill and other areas like Tongaat</li> <li>•Youth participated distributing pamphlets during a community action day</li> <li>•Meeting with lovelife ,SAYC in the province</li> <li>•Hosted provincial HIV/Aids youth conference in mid November</li> </ul>
Western Cape	<ul style="list-style-type: none"> <li>•Condom distribution in various areas, taxi ranks, schools</li> <li>•Meeting with the MEC of health on condom issue and petition</li> <li>•June 16 Youth Day celebrations in Langa sport complex</li> <li>•Meeting evaluating Youth Day and report on the congress resolutions</li> <li>•meeting with NEC with branches in the province.</li> <li>•Meeting with different structures ,ANCYL ,Youth for Work, and many others</li> <li>•Updating schools and engaging them.</li> <li>•Tertiary invading campaign with the institutions UCT ,Pen Tech etc on TAC issues and students</li> <li>•Meeting with aids action committees and other organizations</li> <li>•Provincial youth conference in mid November</li> </ul>
Eastern Cape	<ul style="list-style-type: none"> <li>•A provincial conference took place in the E Cape</li> </ul> <p>They are now working on school programmes, forming action committees</p>
Limpompo	<ul style="list-style-type: none"> <li>•Health talk covering VCT and MTCT</li> <li>•Talk shows in schools was hosted in Malamulele</li> <li>•Meetings with branches, traditional leaders and other stake holders</li> <li>•June 16 hosted commemorative candle light ceremony and other campaigns in Malulele Thoyando</li> <li>•Condom distribution in taverns ,taxi ranks ,garages</li> </ul>
Gauteng	<ul style="list-style-type: none"> <li>•A meeting was held to prepare for the youth camp held in December</li> <li>•Working on engaging other sectors and youth and schools in talk shows</li> </ul>
Mpumalanga	<ul style="list-style-type: none"> <li>•No reports have been received on past activities but they are working on future activities</li> </ul>
National activities	<p>A youth camp, co-hosted with lovelife, took place in Bloemfontein. It went well because we were able to come up with a framework of activities that we want to take up which will get the youth more involved in facing up to their own challenges Here, for the first time, we taught the youth about treatment issues</p> <p>At the treatment congress in Durban the youth played a big role in the commissions which were looking at youth and their role in the national treatment plan. We also had a few meetings with NEC, discussing youth issues, where we took resolutions concerning the representation on NEC of a youth leader to address youth issues within it.</p>

## ***Challenges***

The interest in and dedication of the youth, specifically for youth programmes need to be supported.

Reports need to be submitted monthly for the purposes of accountability. There is a need for provincial coordinators to assist in these programmes.

There needs to be a more active participation by the National Office in youth activities and in planning of campaigns and programmes.

The hosting of the youth camp was a great challenge, especially as it was the first time an event was shared with LoveLife, with the hope of sharing future programmes.

## ***Mobilization***

The sector has managed to mobilize more youth through activities that have taken place, e.g. the workshops we held and the various provinces' activities as reflected above.

We have managed to get the South African Youth Council to take part in activities in some provinces as well as Youth for Work and various other institutions such as lovelife and other youth organizations. We anticipate bringing more on board such as:

- 1.University of Cape Town
- 2.Natal Technikon
- 3.Marianhill Youth Forum
- 4.Imbumba Youth Forum
- 5.Nazo Youth with Vision
- 6.Zola High School
- 7.Newlands High School

We have also been approached by some organizations that have seen our work and would like to co-operate with us who are undertaking youth capacity building.

## ***Developing materials***

So far we have worked with Siphon in trying to develop some materials for schools and the youth in general and we hope to develop more banners and other forms of materials. We have developed a poster and a pamphlet will be coming soon.

## ***Conclusion***

There is a commitment from the youth to forward the struggle against the epidemic. This cannot work without the support from the National Office for the local branches which could play a big role in saving the future generation.

The TAC needs to ensure that young HIV positive and affected youth join hands in the struggle against the epidemic and show their ability to take the struggle forward. To protect the youth is to invest in the future of this country.