JOINT CIVIL SOCIETY MONITORING FORUM

FOUNDED BY THE AIDS LAW PROJECT, HEALTH SYSTEMS TRUST, CENTRE FOR HEALTH POLICY, INSTITUTE FOR DEMOCRACY IN SA, OPEN DEMOCRACY ADVICE CENTRE, TREATMENT ACTION CAMPAIGN, UCT SCHOOL OF PUBLIC HEALTH & FAMILY MEDICINE, PUBLIC SERVICE ACCOUNTABILITY MONITOR & MÉDECINS SANS FRONTIÈRES

Resolutions of the 4th meeting of the JCSMF
Nelspruit, Mpumalanga
20 May 2005

A HOPE FOR A CURE: COMMUNITY STORY

My name is T. I am 36 years old and staying at Mbokota, Limpopo province. I was always sick then I decided to go for an HIV test, the results came positive. I then joined a support group in Elim, where I learnt a lot and met many people. When I was very sick, Dr M arranged for my social grant because I am unemployed.

Last year I went for my cd4 count test and it was 60.The nurses did nothing to help me they just sent me home without referring me to a hospital for antiretroviral treatment. After a year my social grant was stopped. When I went back to the hospital I was told to go and speak with the social worker but she was not there. **Now I am relying on relatives for food and I am struggling to make ends meet.** I hope one day we will be cured.

The JCSMF held its fourth meeting in Nelspruit on 20 May 2005. The meeting was attended by over 18 organisations from the public, private and civil society sectors. The meeting was held to assess the on-going progress of the *Operational Plan for Comprehensive HIV and AIDS Care, Treatment and Management (*Operational Plan).

The meeting reiterated that membership to the Forum is open. It also stressed that the role of the Forum is to support the implementation of the Operational Plan by working with national and provincial health departments as well as with health care workers in all districts.

The meeting had a special focus on nutrition and HIV/AIDS.

It was reported that the Director of Nutrition in the national department of health was invited but was unable to attend. A deputy from her office agreed to attend and make a presentation but cancelled three days before the meeting. The Forum is still awaiting a copy of the presentation.

The forum noted that *inter alia* the Minister of Health, Deputy Minister of Health, Head of HIV/AIDS STD and TB Directorate, Head of the ARV programme and the DG of Health tendered apologies. The Mpumalanga provincial health department was invited but unfortunately could not attend the meeting. The forum welcomed the participation of the head of nutrition in Mpumalanga and appreciated her input and participation at the meeting. The forum also welcomed the participation of the head of nutrition in KZN. For future meetings the Forum resolved to invite, in advance, key national and provincial office bearers.

The forum received a report from the ALP indicating that the total number of patients on ARV treatment in the public sector at the end of March 2005 is 42 000. Dr Nomonde Xundu, Chief Director of the HIV/AIDS / STD and TB Directorate in the NDoH confirmed the figure. Unfortunately, official age and gender breakdowns are not yet available because it will only be presented to Parliament sometime in June 2005. However, provincial breakdowns for Gauteng and the Western Cape as well as latest patient numbers for the Free State are available and were accordingly distributed to participants. Attached is a table indicating the latest patient numbers in the public sector. **See Annexure 1**. Given that at least 500 000 people needed treatment in 2004 – now between 750 000[i] and 837 000[ii] - patient numbers are clearly far lower than what is required. It is crucial that a more aggressive approach to scaling up is taken to avoid falling further behind as the epidemic matures.

The Forum identified the following factors as causes of the failure to meet the need for increased access to treatment:

- Ongoing problems with site accreditation and the lack thereof. Several sites are reported as being ready to commence ARV treatment but are prevented from doing so because they have not been formally accredited. In particular, it was reported that the following hospitals/clinics are ready to treat patients but cannot do so because they have not been accredited: Khensani, Botlokwa, Sheshego and Tintswalo (Limpopo). Hewu (EC). Athlone Park Clinic and Richmond (KZN). Life Care and Witbank (Gauteng). Standerton (Mpumalanga). One of the obstacles to speedier accreditation is that continues to be a centralised function of the NDoH. The Forum calls on the health ministry to ensure that provinces

[i] ASSA 2002
[ii] The Lancet. Predicting the failure of 3 by 5. Vol 365, 7 May 2005

that are in a position to accredit sites themselves can do so with immediate effect. It also calls on the NDoH to accredit the above-mentioned sites.

- There is still no Human Resources Plan that addresses short, medium and long-term needs. In 2004, the Department of Health indicated that it was drafting a Plan, which would be ready for public comment by March 2005. This has not happened. The Forum calls on the department to explain its failure in developing a Plan that at the very least addresses the emergency HR needs of all the provinces and to also indicate to the public when such a Plan will be available for public debate.
- Long waiting lists in many provinces and treatment sites that have placed caps on patient numbers for the year 2005/2006 are limiting access and slowing down the pace of the rollout. The forum received reports indicating that several sites have long waiting lists. This means that many sites are not managing the demand for treatment that exists and therefore require, at a minimum, additional human resource allocations as well as provincial and national support to avoid further, unnecessary and premature suffering and death. Reports indicate that the following sites have waiting lists: Letaba 2 months (Limpopo); Tshnidzini 4 months (Limpopo); Stanger 500 patients are on the waiting list (KZN); Prince Mshiyeni (the exact period is unclear) (KZN); Far East Rand Hospital 4 months (Gauteng). It was reported that Chris Hani Baragwanath Hospital has now managed to reduce its waiting period from a few months to 3 weeks. It was also reported that some sites are placing caps on patient numbers, artificially limiting the number of patients that can be treated. In particular, Pretoria Academic Hospital (Gauteng), R K Kahn (KZN); King Edward (KZN); Mt Frontier (EC). The Forum resolved to investigate the basis for imposing the caps.
- At the last Forum meeting it was reported that the unwillingness or inability to treat children has resulted in very few children being put on ARV treatment. The Forum heard that this trend is continuing with fewer than 4500 children on treatment in the whole country where the need is estimated to be at least 50 000. The Forum repeats its call on the NDoH to take urgent steps to ensure that all treatment sites treat children as well. In this respect, the Forum notes that a group of concerned paediatricians have offered to assist the NDoH and provinces with training and other support.

Nutrition

The focus of the meeting was on nutrition. In recent months the Minister of Health has chosen to focus on access to nutrition as being an essential component of care for people living with HIV/AIDS. The meeting therefore (a) clarified some of the issues around HIV and nutrition and (b) examined the extent to which government is meeting the nutritional requirements of poor people in South Africa, in line with its commitments in the Comprehensive Plan and with its constitutional duties to take measures to ensure that "everyone has the right to have access to sufficient food and water" and that a child's right to "basic nutrition" is fulfilled.

The Forum noted that it is widely accepted that there is a lack of food security in South Africa; that there are high levels of unemployment and poverty; and high levels of chronic malnutrition in all parts of the country. Against this background, the Forum recognised that it will be difficult to implement an integrated nutritional programme without simultaneously addressing and undoing the causes of poor nutrition.

It was reported that existing nutrition programmes include:

(a) The National Emergency Food Programme (NEFP) to improve food insecurity

(b) The Nutrition Supplementation Intervention for people with TB and HIV, which provide supplement meals and micronutrients.

According to the Operational Plan, the Department of Health is responsible for coordination interdepartmental nutritional programmes and developing nutritional training materials.

At a provincial and national level:

- The National Nutrition Guidelines (2001 and updated in 2003 and re-printed in 2005) are being revised by the NDoH to incorporate the Operational Plan. Some provinces such as KZN, Gauteng and WC have already drafted their own set of nutrition guidelines.
- The Operational Plan sets out the health policy on Nutrition, and in particular, states *inter alia* that:
    - The plan is to target communities by giving them general information on nutrition with emphasis on HIV and AIDS needs,

- Government seeks to put into practice a comprehensive nutritional programme with the introduction of HIV/AIDS care and treatment - -Implementation of the plan will be within the existing government policies and strategies aimed at reducing poverty.

With regard to eligibility – the Operational Plan states *inter alia* that:

- People without food security will receive vitamin supplementation,
- All HIV positive children under the age of 14 who enrol at service points should receive nutritional packages consisting of vitamin syrup and a supplement meal,
- Pregnant woman in need should also get supplement meals to ensure their food security
- HIV/AIDS care and treatment programme provides for supplement meals for all people living with clinical AIDS who are malnourished and eligible for ARVs and who do not have access to food supply, and
- HIV positive people attending service points for HIV treatment should receive counselling and materials on healthy eating and food preparation.

Despite these undertakings, the Forum received three reports from people living with HIV/AIDS in Mpumalanga who indicated that there are serious problems with the implementation of the nutrition programme in Mpumalanga. Their stories and testimonies paint a bleak picture of the extent to which nutritional support is available to poor communities. In particular, they stated that:

i. Food parcels and supplements are not available at all clinics in the area,
ii. They have not received proper counselling about nutrition at treatment sites, and
iii. Food parcels sometimes get rotten at hospitals or are stolen.

The head of nutrition in Mpumalanga undertook to investigate the above reports and stressed that communities have to inform the province about problems encountered in attempting to access nutritional support so that appropriate measures can be taken to remedy them. The development of mechanisms whereby community members can actively participate and inform the relevant departments of such issues is therefore needed.

The Forum received a report from the IDASA's AIDS Budget Unit on national HIV and AIDS budgetary allocations for this financial year as well as conditional grant funding for the National School Nutrition Programme (NSNP) and the Integrated Nutrition Programme (INP). IDASA reported that while the INP has seen an increase in expenditure over the last few years, these have not been substantial. The INP also has a much smaller budget compared to the NSNP budget. However, from next year the INP will be funded only from

provincial equitable share allocations. So the provinces will be monitored to see if they actually allocate resources from their own budgets for this programme.

The Forum noted that the nutrition portion of the HIV/AIDS conditional grant in the Operational Plan cannot be assessed given that reporting on the budget is not disaggregated. The Forum therefore calls on government to ensure that the Operational Plan conditional grant spending reports are disaggregated at provincial level so that it is clear how these amounts are being spent.

The PSAM reported that in the Eastern Cape aside from the continuing and worrying trend of under spending of the health budget, there are backlogs with regard to spending funds allocated for the Integrated Nutrition Programme (INP).

The Forum therefore calls on the Eastern Cape Provincial government to ensure that the backlogs are addressed and that feeding at schools continues.

While it may not have been possible for the Forum to compose a national picture of access to nutrition, anecdotal evidence suggests that the programme is fragmented, uneven and beset by problems.

For example, it was reported by Dr Moultrie a paediatrician at Chris Hani Baragwanath Hospital, who works at the Harriet Shezi Clinic, the largest paediatric treatment site in SA, that only 6% of children on ARV treatment at Harriet Shezi have access to fortified maize meal (through the dietician) but no access to food parcels. In respect of the latter he reported that often social workers are not available to advise patients on where and how to access food parcels and supplements. In addition, at times, social workers are themselves unaware of the criteria that have to be met by patients to qualify for food parcels resulting in fewer patients accessing them. He indicated that the bureaucracy involved in accessing food parcels and other nutritional support makes it difficult for patients and their caregivers to access benefits. For example, in order to qualify for a food parcel, a social worker has to first complete a 5-page assessment. At Harriet Shezi, there are about 1200 children attending the clinic and 1600 adults on ARV treatment. This means that it will be almost impossible for the social worker to administratively manage to assist every patient in need. It was noted that as at end April 2005, none of the paediatric patients and adult patients at Harriet Shezi were receiving food parcels.

Serious gaps in the nutrition support programme at facility level exist. These include a shortage of social workers and nutritionists in the country, lack of proper guidelines, inadequate resources and poor supervision. This, coupled with logistical delays in getting food parcels to facilities adds to the ongoing weakness of the programme.

The Forum resolved to vigorously and consistently monitor nutritional support provided to all communities.

The Forum received a report from Dr Hugo Templeman at Ndlovu HAART programme, which is based in Mpumalanga. Ndlovu commenced its HAART programme in 2003. It is the only community project in the country with its own HIV monitoring laboratory – given the high costs of laboratory monitoring this is a significant cost saving initiative. Dr Templeman indicated that Ndlovu has offered to work with the provincial government – but to date the offer has not been taken up. Ndlovu offers MTCT, ARV treatment, obstetric services, VCT and nutritional support and assistance – as part of a comprehensive response to HIV/AIDS. As at May 2005 it had 23 children on treatment and 340 adults on treatment.

The Ndlovu nutritional programme was started in 1996. It targets malnourished children and caretakers. Through education and support in forming vegetable gardens using home visits many families have been assisted with starting their own gardens. The nutritional unit is assisting 40 mothers and their children. The latter works with the local communities in arranging for food parcels through a food voucher system. One of the problems identified is abuse of the system given massive unemployment and hunger

The programmes MTCT success rate is phenomenal. Of 44 patients, none have transmitted HIV to their babies – the programme is using a triple therapy regimen from 20 weeks and provides one year's supply of formula feed.

Given the skills and expertise developed by several community treatment projects in the country such as Ndlovu HAART the forum calls on the provincial government of Mpumalanga and the NDoH to work more closely with community treatment projects. Further, the feasibility of setting up monitoring laboratories such as the one at Ndlovu should be further investigated so that communities without easy access to laboratory services can replicate the Ndlovu experience.

Role of Nutrition for all people - including those living with HIV

The Forum was privileged to receive an important scientific presentation on 'Nutrition and HIV/AIDS' from Professor Nigel Rollins of the University of KwaZulu-Natal Nelson Mandela School of Medicine. **See Annexure 2.**

Based on Professor's Rollin's presentation, the Forum records:

- Poverty and the endemic lack of food security are major national challenges
- Jobs and access to income are the most important means to food and nutrition security. On this basis, the Forum reiterated its support for the introduction of a Basic Income Grant (BIG).
- Everyone requires food security. Everyone requires good nutrition; including people living with HIV/AIDS and everyone has protein, vitamin, mineral and energy needs. Critical treatment such as ARVs may not achieve its full benefit without appropriate and adequate nutrition.
- That there must be equity for all people who need access to food and nutritional supplements, irrespective of their HIV status.
- That there is insufficient scientific and evidence based studies about the interaction between nutrition and HIV/AIDS. As such, there is no scientific evidence to suggest that good nutrition alone can treat HIV. While good nutrition is important for everyone including people living with HIV/AIDS, there comes a point where it is medically necessary to commence ARV treatment. Additional studies are urgently needed, including operational studies, of how nutrition can best be integrated into care programmes. Clinical studies are also needed to determine the effect of nutritional interventions in delaying early disease progression and also the interaction on nutrition and ARVs – for example, absorption and adverse events.
- It is necessary to be clear and accurate about the role of nutrition in the management of HIV/AIDS. Public messages about nutrition and its role in the management of people living with HIV/AIDS should not mislead the public into believing that nutrition alone can treat HIV/AIDS or that all HIV-infected patients require nutritional supplementation.
- The Forum supports the *Participants Declaration* issued at the WHO Consultation on Nutrition and HIV/AIDS in Africa held in Durban recently. In particular, that:

i. Far reaching steps need to be taken to reverse the current trends in malnutrition, HIV-infection and food insecurity in most countries in the region, in order to achieve the Millennium Development Goals (MDG).
ii. Adequate nutrition cannot cure HIV infection but it is essential to maintain the immune system and physical activity, and to achieve optimal quality of life.
iii. Adequate nutrition is required to optimize the benefits of antiretroviral drugs (ARVs), which are essential to prolong the lives of HIV-infected people and prevent HIV transmission from mother-to-child.
iv. There is a proliferation in the marketplace of untested diets and dietary therapies, which exploit fears, raise false hopes and further impoverish those infected and affected by HIV and AIDS.
v. Exceptional measures are needed to ensure the health and well-being of all children affected and made vulnerable by HIV/AIDS. Young girls are specially at risk.
vi. Knowledge of HIV status is important to inform reproductive health and child feeding choices.

- HIV care, including ARV treatment, provides an excellent entry point into programmes aimed at meeting nutritional needs where indicated on an individual basis. However, focusing on adequate amounts of nutritious food is the first priority before considering micro-nutrient supplementation.
- Dietary and nutritional assessments must become a standard part of comprehensive care in our health services, regardless of HIV status. Here it is important to distinguish nutrition as a basic health requirement from alternative diets, which might include foodstuffs that have certain medicinal 'qualities' – such as garlic.

Protecting people from exploitation and unsubstantiated claims about nutrition and food

- The Forum notes the vulnerability of people living with HIV to exaggerated or unfounded claims about food and vitamin preparation
- The Forum calls on the Medical research Council (MRC) to carry out an independent investigation into claims being made by Tine van der Maas, concerning the nutritional or medicinal value of a combination of foods, which she claims, are of great benefit for people living with HIV. These combinations must be tested and proven in an acceptable manner.
- The Forum condemns the repeated public attacks by Matthias Rath about the safety of ARV treatment. It also examined his unsubstantiated claims regarding the impact of micronutrients on HIV progression, and the manner in which his Foundation is misrepresenting scientific studies of micronutrients and HIV.
- The Forum calls on leaders in the nutrition industry to ensure that its advertising of nutrition and micronutrient supplements is accurate and ethical.
- The Forum calls on the NDoH and MCC to ensure that an adequate regulatory framework is put in place for untested health products.

The Forum emphasised its commitment to supporting the implementation of the Operational Plan. For civil society to work in collaboration with government, accurate and updated information about the state of implementation of the Operational Plan in each province is vital. Where this is absent, it makes it very difficult for civil society to assist. The meeting therefore concluded that the NDoH and government must work more closely with civil society. Again, the Forum repeated that its aim is to make the Operational Plan work, not to revel in its limitations.

The next meeting of the JCSMF will be held during August 2005 in CAPE TOWN.

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Annexure 1

BEST ESTIMATES COMPILED BY ALP MAY 2005

Province	**Target 2004 (Rev. 2005)**	**Numbers on treatment (Adults and children)**
Gauteng	10 000	**12 412 March 2005** (Adults 10 916) (Children 1496)
North West	1 808	2625 (Jan 2005)
Northern Cape	790	700 - 800 (Jan 2005) (Adults 500 – 600) (Children 200-300)
Eastern Cape	2750	3739 (Jan 2005)
Western Cape	2728	**7670 (March 2005)** (Adults 6386) [Province 4480 Donor 1906] (Children 1284) [Province 1168 Donor 116]
KZN	24 902	**11 000 (March 2005)** 13000 with donors (Adults 90%) (Children 10% - 900)
Limpopo	6965	935 (Jan 2005)
Mpumalanga	1934	936 (Jan 2005)
Free State	2127	1785 (March 2005) Male 509 Female 1024 Children 156 Catholic Relief 60
TOTAL	**54 004**	**42 000**

Annexure 2

Prof Rollins presentation …