

**The South African “Roll-out” of anti-retroviral medicine for people living with AIDS: testimony from front line workers. What does this programme look like “from below”?**

**THE ISSUES THAT WE ADDRESSED IN OUR RESEARCH:**

South African provision of medicine for people who are HIV-Positive is the largest programme of its kind in the world. By 2015 the number of people receiving anti-retroviral (ARV) drugs had reached 3.1 million, about half the total population that is HIV-positive. That is what the national statistics are telling us. In our research we wanted to find out what this programme looks like at its base level, in its most localised settings, among the communities serviced by the 3,500 clinics that dispense the medicine.

When the treatment programme expanded away from its original centres in the hospitals to become a major responsibility for the primary health care system, from 2009 onwards, many key functions needed to support the programme would be supplied by volunteers, some of whom would become recipients of stipends from the government. Today there are about 75,000 of these ancillary workers engaged in the “roll-out” of treatment

for people living with AIDS, in addition to the nurses at the clinics – in 2012 there were 10,000 of these, qualified to initiate ARV prescriptions. So, the dependence of the programme on auxiliary and semi voluntary workers who are not formally employed by the government is acute. It saves the government money and it draws upon voluntary kinds of idealism and commitment. Without this kind of community-based support for the programme, progress in treating HIV-positive people would have been much slower and much more expensive. We wanted to find out if the division of labour between medical professionals and community workers is effective in the long term? Can it be sustained?

**METHODS: HOW DID WE INVESTIGATE THIS QUESTION?**

First we ran three focus groups assembled from full time Treatment Action Campaign (TAC) activists and we asked them to speak about their day to day experiences in monitoring the roll out in three provinces, Gauteng,



KwaZulu-Natal and Limpopo. After helping us to construct a questionnaire and undergoing a brief training session, the activists then interviewed individually on our behalf a total 55 Community Health Workers. We also conducted our own interviews with a leadership group within the TAC, Section 27, public health officials and the South African National AIDS Council (SANAC).

## WHAT DID WE FIND OUT?

When we did the research most Community Health Workers were managed by NGO's which pay them the stipends supplied by provincial departments of health. In 2015 stipends varied: between R500 and R1,500 a month. Official policy favours a "re-engineering" of the primary health care system so that the workers will constitute "outreach teams" managed directly by clinical staff – nurses, mainly, and the workers will receive their stipends directly from the government, paid into their bank accounts. But this change is not intended to make them employees: they will remain individually contracted "service providers". The change will cut out the role of the NGO's that in the past have managed the Community Health Workers. In our group, the Limpopo and Gauteng workers were still NGO-managed, though in the case of Limpopo working under close supervision by nurses at the clinics. In KwaZulu Natal our interviews were being stipended directly by the provincial Department of Health and had joined outreach teams.

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What do these workers do for the programme? They used to be very important in the provision of pre-treatment counselling – but they seem to do less of this now as pre-treatment preparation has become more abrupt and cursory. This is a problem: high proportions of patients do not return for treatment after testing and more effort needs to be invested in persuading them to do so. From the interviews it became clear that they still make a very important contribution to home-based care of very sick people, a function that "re-engineering" is intended to confine to a separate group of carers. About half the people interviewed spoke about the help they give patients in their homes, including cleaning and helping patients to eat and exercise. They also help patients obtain food parcels and sometimes secure charity on their behalf, undertaking door to door collections. Aside from meeting these needs, the workers undertake key medical functions including "Directly Observed Therapy" that is systematic monitoring of TB patients taking their medicine, ensuring patients take their ARV pills on time, and in KwaZulu Natal running "adherence clubs" to encourage patients to maintain their commitment to treatment. They are the key people in tracing treatment "defaulters" and persuading them to return to medication. At the clinics they function as paramedical auxiliaries, helping nurses screen patients for TB and undertaking other kinds of testing as well as organising queues and doing public health education, at the clinics and in door to door visits.

What are the likely effects of re-engineering? The changes in the ways that these workers have been managed have been welcomed by the workers themselves: generally re-engineering has been accompanied by more efficient payment of stipends and in the long term stipends are meant to become standardised – and for many the rates will improve. Deployment in clinically managed outreach teams is viewed by the workers as an improvement in their status and recognition of the importance of their contribution to the programme. However the new arrangements still fall short of what many of them seem to want, that is to become full members of the public sector with secure jobs and benefits.

There are risks in "re-engineering". As the workers become increasingly deployed as clinical auxiliaries supervised directly by nurses it is likely that much of the home-based care and other kinds of community activity they undertake on their own initiative will stop. Some of our Limpopo informants found they were increasingly engaged in clinic-based screening activity. As importantly, as workers who still see themselves as "volunteers" answerable to community-based organisations they retain critical independence. Several of the worker interviewed



**6.3** million people living with HIV

**19.1%** adult HIV prevalence

340,000 new HIV infections

200,000 AIDS-related deaths

**42%** adults on antiretroviral treatment

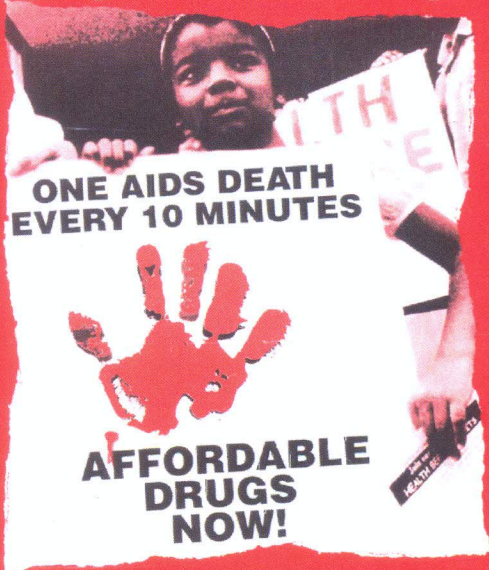
Source: UNAIDS Gap Report 2014

These risks reflect real issues. Official projections for the numbers of workers who will be stipended are well below the existing total. The Department of Health has also set “case-load” quotas for the workers which suggest that they will provide much more perfunctory kinds of care than the range of attentive support evident in the testimony we collected. Tracing defaulters and encouraging adherence are not activities that lend themselves to quota-based performance evaluation. And we know from nationally available statistics that large numbers of patients are “lost to follow-up” after beginning ARV treatment. In the Free State “re-engineering” has already lead to the exclusion of experienced community health workers, ostensibly because they lacked formal educational qualifications. As proportion of the people we interviewed didn’t have the certificates the new rules will require. In fact the programme needs more support; many of the workers the TAC activists interviewed complained of being shorthanded.

**Join the Treatment Action Campaign (TAC)**

# **Global March for Access to HIV/AIDS Treatment**

**9 July 2pm Durban City Hall**



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## CONCLUSIONS AND IMPLICATIONS FOR PUBLIC ORGANISATIONS

The reorganisation of this important group of ancillary workers seems to be based on an incomplete understanding of the functions they perform. Conceptualising their role as “outreach” seems to downgrade and simplify the supports they provide for people living with aids. The danger of turning these workers into auxiliary nurses is that the roles they play both in maintaining patients’ adherence to treatment and in monitoring the effectiveness of delivery will weaken.

### POLICY RECOMMENDATIONS AND KEY LEARNING

The NGO’s that manage these workers can be inefficient but they are not always so. The original functioning of the programme through a partnership between the public sector and community-based organisations as well as more specialised NGO’s checked inefficiencies. The oversight supposed to be supplied by local SANAC committees is very uneven in quality and often absent. Re-engineering needs review.

### MORE READING

Jonni Steinberg supplies a vivid description of the daily routines of a community health worker at a time when the treatment programme was being pioneered in the Transkei. See his *Three Letter Plague* (Jonathan Ball, Johannesburg, 2008, pp. 166-184).

A national audit of community-based health workers was undertaken for the Department of Health in 2011. See South African Department of Health, 2011, CHW Audit Report.

For a broadly positive view of primary health care “re-engineering” see Helen Schneider, Rene English, Hanini Tabana, Thesandee Padayachee and Marsha Orgill, 2014, “Whole system change: a case study of the factors facilitating early implementation of a primary health care reform in a south African province”, BMC Health Services Research, 14: 609 <http://biomedcentral.com/1472-6973.14/609>

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