

# Comprehensive TB/HIV Services at Primary Health Care Level Khayelitsha Annual Activity Report 2007-2008



**Médecins Sans Frontières**  
**Western Cape Province Department of Health**  
**City of Cape Town Department of Health**  
**University of Cape Town, Infectious Disease Epidemiology Unit**



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## Introduction & Brief History

Khayelitsha, a large township with around 500,000<sup>1</sup> inhabitants located on the outskirts of Cape Town, has one of the highest HIV prevalence rates in South Africa. The majority of the population lives in informal housing, and there are alarming rates of poverty, unemployment, and crime, including sexual violence. Khayelitsha carries one of the highest burdens of both HIV and tuberculosis (TB) in the country. In 2007 antenatal HIV prevalence was 30.2%, and 31% of all adults on antiretroviral therapy (ART) in the Cape Town Metropolitan area are treated in Khayelitsha. The TB incidence rate reached nearly 1,600 per 100,000 in 2006, and TB/HIV co-infection is close to 70%.

In January 1999, the Western Cape Department of Health launched a pilot programme to prevent mother-to-child transmission (PMTCT) in Khayelitsha at the Site B Day Hospital which was the first government-run PMTCT programme in South Africa. This programme was supported by Médecins Sans Frontières (MSF).

In early 2000, MSF and the Provincial Administration of the Western Cape (now the Provincial Government of the Western Cape or PGWC) started an HIV/AIDS care and treatment programme at the primary health care level via three community health centres. In May 2001, the first patient was initiated on ART, after a long struggle to obtain access to affordable quality generic antiretrovirals (ARVs).

Initially the aim of this pilot programme was to demonstrate feasibility of ART at the primary health care level in a resource-limited, peri-urban setting. As of 2004, objectives changed toward scaling up and the Khayelitsha ART programme was fully integrated into the Provincial ART Programme. Nowadays, the Khayelitsha programme aims to show the feasibility of achieving the targets set forth in the National Strategic Plan (NSP) for HIV/AIDS and Sexually Transmitted Infections (STIs), including achieving "universal coverage" of ART needs by 2011.

Since its inception, the Khayelitsha programme was developed in close collaboration with both the Western Cape Department of Health (DOH) and the City of Cape Town Health Services. Khayelitsha is a provincial sentinel monitoring site and receives significant technical support from the Infectious Disease Epidemiology Unit of the School of Public Health and Family Medicine at the University of Cape Town (UCT). Many local nongovernmental organisations have played a critical role in the success of this programme, with the Treatment Action Campaign (TAC) being particularly important in promoting openness about HIV and empowering people living with HIV/AIDS (PLWHAs) through treatment literacy and other strategies.

Since this pioneering programme was launched more than seven years ago, over 10,000 people have successfully been started on life-saving ART at seven sites in Khayelitsha. More than 93% of them are today alive and remaining in care.

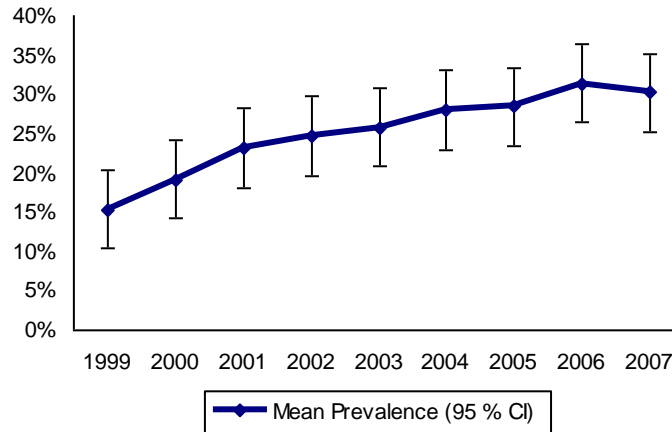
This report provides an update of major outcomes and developments in the provision of HIV and TB services and highlights key clinical, programmatic, and policy changes necessary to continue to meet the ever-increasing need for HIV and TB care and treatment in Khayelitsha.

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<sup>1</sup> The actual population of Khayelitsha population is unknown. This figure is based on a 2001 census, and is widely believed to be underestimated, which makes coverage and other figures difficult to estimate.

## Evolution of HIV Prevalence

HIV prevalence among women presenting for antenatal care (ANC) has been routinely measured since the beginning of the prevention of mother-to-child transmission (PMTCT) programme in 1999 (Figure 1). Since 2003 more than 95% of mothers presenting for their first ANC visit have accepted HIV testing.



**Figure 1.** Khayelitsha Antenatal HIV Prevalence 1999-2007

Between January 1999 and 2005, the antenatal HIV prevalence doubled from 15 to 30%, reached a peak at 32.5% in 2006, and then dropped again slightly to 30.2% in 2007. As can be seen from the above graph, confidence intervals overlap, and it would be premature to say that this signals a reduction in prevalence, although lower prevalence rates are observed for younger age groups.

## Voluntary Counselling & Testing (VCT) Services

In 1998, only 450 HIV tests were carried out in the sub-district of Khayelitsha. Large scale voluntary counselling and testing (VCT) started with the PMTCT programme in 1999. This was made possible through the employment of lay counsellors and the use of on-site rapid tests. In 2002, there was a further increase in numbers as routine testing was introduced into the TB services.

Year	2003	2004	2005	2006	2007
Tested	16,024	20,576	26,681	32,383	32,069
Positive	4,928	6,474	8,804	9,691	8,749
%HIV +ve	31%	31%	33%	29.9%	27.3%

**Table 1.** VCT (all including PMTCT) in Khayelitsha 2003-2007

Nowadays, routine ('opt-out') HIV testing is being implemented in PMTCT, TB, and STI services. As a result of this strategy, the numbers of people tested increased sharply in 2005 and 2006 but seems to have reached a saturation point in 2007.<sup>2</sup> This calls for alternative testing points as well as adapting HIV testing messages and strategies to people who have already tested. The public education work around testing needs to move from encouraging people to know their status to encouraging them to test regularly when tested HIV negative, at least once a year.

When comparing Khayelitsha with the other sub-districts in the Metropolitan area, despite achieving the highest percentage of the adult population tested, it plateaus at 13% of the total population. The NSP target is to test 11% of the adult population in 2008, but increases to 24% in 2011. In other words, the percentage of people being tested needs to nearly double within the next three years. This will not be achieved with conventional, facility-based VCT only.

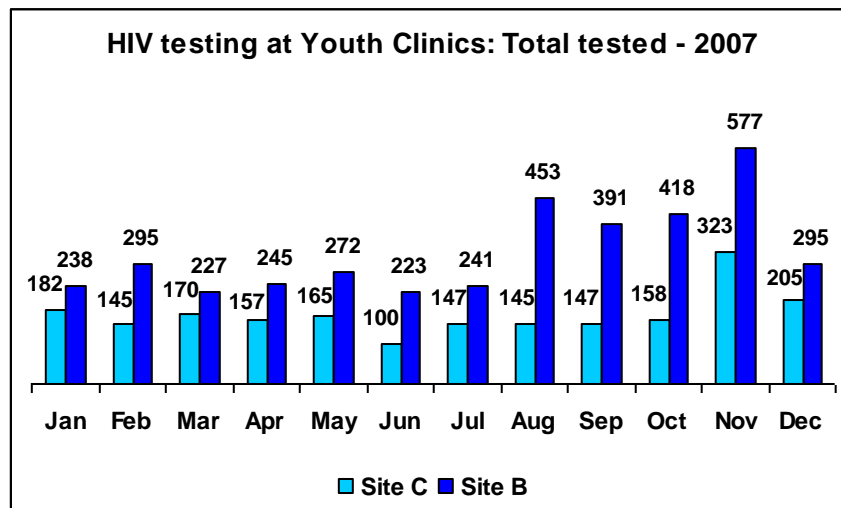
The large burden of HIV in Khayelitsha will require that innovative strategies be found to improve access, reduce stigma, and increase uptake of services. Community-based HIV "wellness services" for HIV-positive people not eligible yet for treatment have still to be properly implemented in Khayelitsha. This is an important priority for the future.

### Accelerated Counselling & Testing Strategy at Youth Clinics

Two dedicated youth clinics (for people < 25 years of age) have been opened in Khayelitsha: Site C Youth Clinic was built by MSF in 2004 and Site B Youth Clinic was built by the Evangelical Church in 2006. Both these clinics are major service points for family planning and STI treatment in youth. They offer a major potential for prevention and increased uptake of VCT.

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<sup>2</sup> A population survey done in 2003 showed that 42% of all adults interviewed had been tested at least once for HIV.



**Figure 2.** HIV testing at Youth Clinics 2007

In 2006, the City of Cape Town implemented a pilot programme of routine ('opt-out') testing for youth ("accelerated counselling and testing" or ACTS). This led to an immediate increase of HIV testing rates amongst youth, and further increases were experienced in a revival of that pilot testing strategy in late 2007. Interestingly, the female to male ratio has been at 60:40, slightly above the existing ratio in adults, and the positivity rate is lower.

### **Male Walk-In Clinic in Site C**

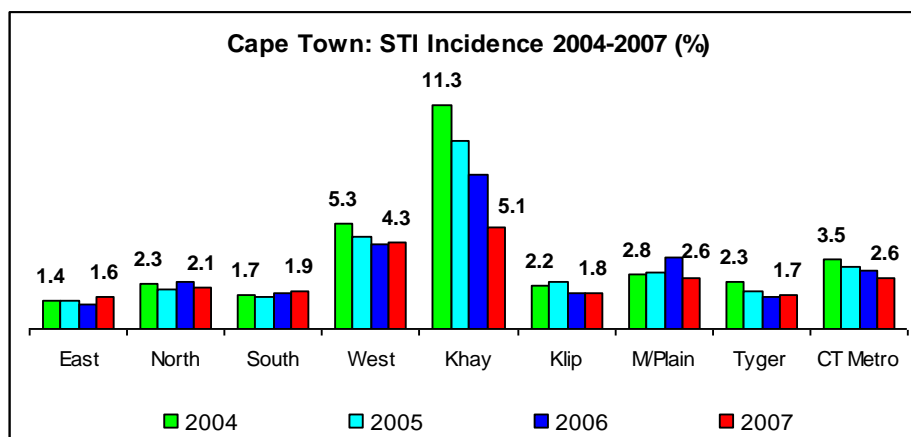
A new service dedicated to reaching men and offering VCT and treatment of STIs at Site C taxi rank was opened at the end of 2007 as a pilot to test the impact of such a clinic on improved male access to HIV testing, a major challenge in Khayelitsha and elsewhere. This initiative is a partnership between PGWC, City Health, Hope Worldwide, and MSF.

Initial results show a rather slow take-off in the testing rates, although there has been a steady increase: the number of people tested increased from 128 in January to 213 in June.

Importantly, after just six months of functioning, this clinic treats more STIs in Khayelitsha than Spencer Road clinic, which was the major STI treating site for men, including those in Khayelitsha, prior to opening the male walk-in clinic.

## HIV Prevention

Khayelitsha represents approximately 11% of the total population in the City of Cape Town but 34% of the total STI case burden (2004 data). Male condom distribution has been a major priority for health providers and NGOs such as TAC and their efforts have resulted in an increase in condom distribution from 2.7 million in 2004 to 12 million in 2007. The focus of distribution shifted from health facilities to public distribution sites (public toilets, libraries, taxi ranks and "shebeens"). During this three-year period, a 50% drop in STI incidence was reported in Khayelitsha (Figure 3).



**Figure 3.** Annual percentage of adults treated for STIs (2004-2007)

## Prevention of Mother-to-Child Transmission (PMTCT)

In December 2004, a pilot project was established to initiate ART for pregnant women with CD4 counts below 200 cells/ $\mu$ l at the midwife obstetric units (MOUs) at primary care level. This strategy is particularly relevant now that the new national PMTCT guidelines have been revised to recommend ART for all HIV-positive pregnant women with CD4 counts <250 cells/ $\mu$ l and dual therapy for those with CD4 counts > 250 cells/ $\mu$ l.

The anticipated benefits to this model of providing ART at the MOUs were the following:

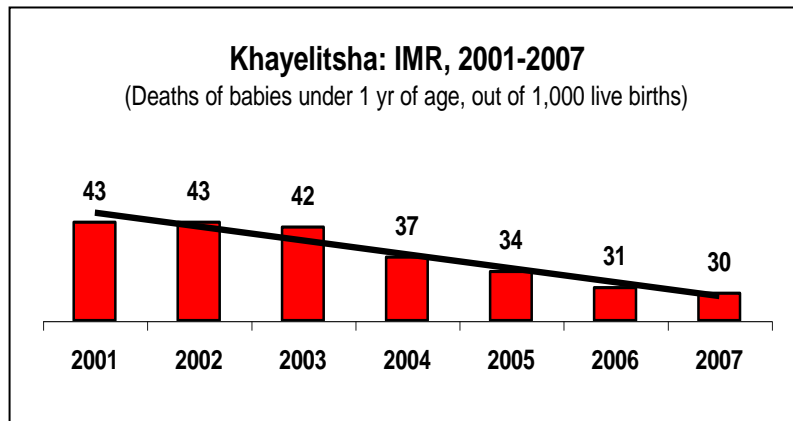
- Potential for reduced maternal morbidity through higher ART uptake
- Potential for reduced transmission of HIV from mother to child
- Fast-track system allows for women presenting late in their pregnancy to benefit from ART
- Strategy may reduce number of losses to follow-up for ART during pregnancy
- One-stop service saves time for both the patient and the health services
- Involvement of MOU staff in ART

This pilot continued successfully in Site B MOU. The ART clinic was partially integrated within general maternal and child health care with support of Mowbray obstetricians, trained by MSF in ART. An evaluation of the strategy is underway.

The rate of vertical transmission in Khayelitsha for the first half of 2007 as measured by HIV DNA polymerase chain reaction (PCR) at six weeks (73% of exposed newborns tested) was 3.5%. This impressive figure is the result of 10 years of aggressive PMTCT which has led to a testing acceptance rate close to 100%, an active promotion of exclusive formula feeding with provision of infant formula milk for the first six months (as per the mother's choice), and an aggressive PMTCT drug regimen (AZT ante-natally from 28 weeks plus single-dose nevirapine for the mother and AZT for seven days post-natally for the baby, whereas nationally, only single-dose nevirapine was

implemented to reduce vertical transmission). Through this programme, HIV transmission has been prevented in hundreds of babies each year.

Furthermore, Khayelitsha has recorded a steady decrease in infant mortality since 2004 (Figure 4), showing a clear impact at population level of the PMTCT, including extensive acceptance of formula feeding.

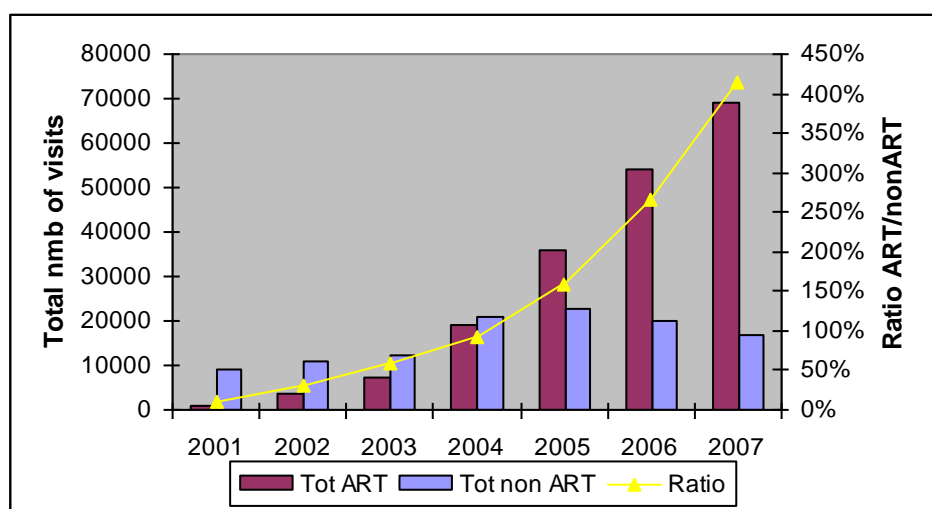


**Figure 4.** Decrease of infant mortality in Khayelitsha (2001-2007)



## Evolution of HIV Consultations & Integration into PHC Clinics

The number of consultations at the three ART clinics at CHCs in Khayelitsha (Ubuntu/Site B, Nolungile/Site C, Michael Mapongwana ) has increased very rapidly, almost doubling each year between 2005 and 2007 to reach over 87,000 consultations in 2007 (Figure 5). A major focus on "task-shifting" to nurses supported this increase in patient load, albeit with a high level of over-saturation and congestion. This "de facto" nurse-based policy has been implemented in all three CHCs. However, such a nurse-led, doctor-supported service model has only recently been accepted at provincial level and the regulatory framework is still under development.



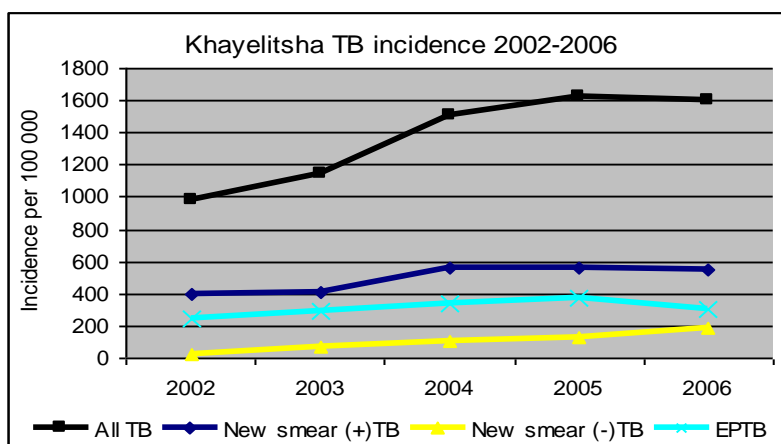
**Figure 5.** Evolution of ART/non ART consultations in the 3 existing ART clinics

The total number of consultations in the three dedicated ART clinics in Khayelitsha continued to increase sharply in 2007 with a total of 87,289 consultations compared to 56,547 in 2005. Of these, 6,535 (7.7%) were children below 14 years of age compared with 3,921 in 2005 (6.9%). The total number of newly admitted patients in the three clinics was 2,322 in 2007, a figure slightly lower than in 2005. Although the number of new admissions has not increased, the cumulative patient load results in an additional workload for the clinics. As such, a priority was given in 2007 to reducing the burden of stable ART patients on clinical staff (see section on adherence support below).

HIV care decentralisation and integration at primary care level (three CHCs and most existing City clinics) played a critical role in coping with the ever-increasing workload. The number of medical doctors has not increased significantly in any of the three CHCs since 2005 despite several attempts to change this. Doctors are needed to consult on complicated cases and to provide clinical supervision and it is therefore necessary that vacant posts be filled. But perhaps more urgent is the need to continue to support task-shifting to other categories of staff, particularly nurses. Indeed, this will be a mandatory condition to achieve the NSP targets. This will only succeed if "enabling factors" are rapidly implemented: extensive training and coaching, improved conditions and incentives, improved packages for nurses, career-pathing, and improved supervision and quality control.

## The TB Epidemic in Khayelitsha

In 2006 in Khayelitsha, TB incidence was 1,596 per 100,000 which amounted to 5,884 new TB cases. The TB/HIV co-infection rate was 67%. TB incidence has been rising since the early 2000s. The number of new cases diagnosed reached a plateau in 2006.



**Figure 6.** TB incidence in Khayelitsha 2002-2006

The City of Cape Town has been reporting very good TB treatment outcomes. In 2006, the cure rate of new smear-positive cases was 76% and the treatment success rate was 82%. Khayelitsha was just marginally below that at 74% cure rate and 80% treatment success rate.

### TB-HIV Integration

Given that HIV and TB are two diseases that often affect the same patient and given limited available health staff in Khayelitsha, integration of the two programmes became a priority in 2003. During that year, a pilot clinic was launched—the Ubuntu clinic in Site B—where TB and HIV services, including ART, were integrated. This model has since been extended to other clinics in Khayelitsha.

Routine HIV testing has resulted in a doubling in the proportion of TB patients being counselled and tested since 2002. In 2007, 99% of TB patients received counselling and almost all of them (95%) accepted to be tested. Of these, 67% were found to be HIV-positive. Almost all of those testing positive (99%) had a CD4 count done, which allowed for rapid enrollment into care for those in need of ART.

Khayelitsha: VCT in TB services			
	Proportion TB patients counselled	Proportion accepted testing	Proportion testing HIV +
2002	49%	89%	26%
2003	62%	84%	45%
2004	62%	87%	73%
2005	72%	91%	76%
2006	99%	95 %	67%
2007	99%	95 %	67%

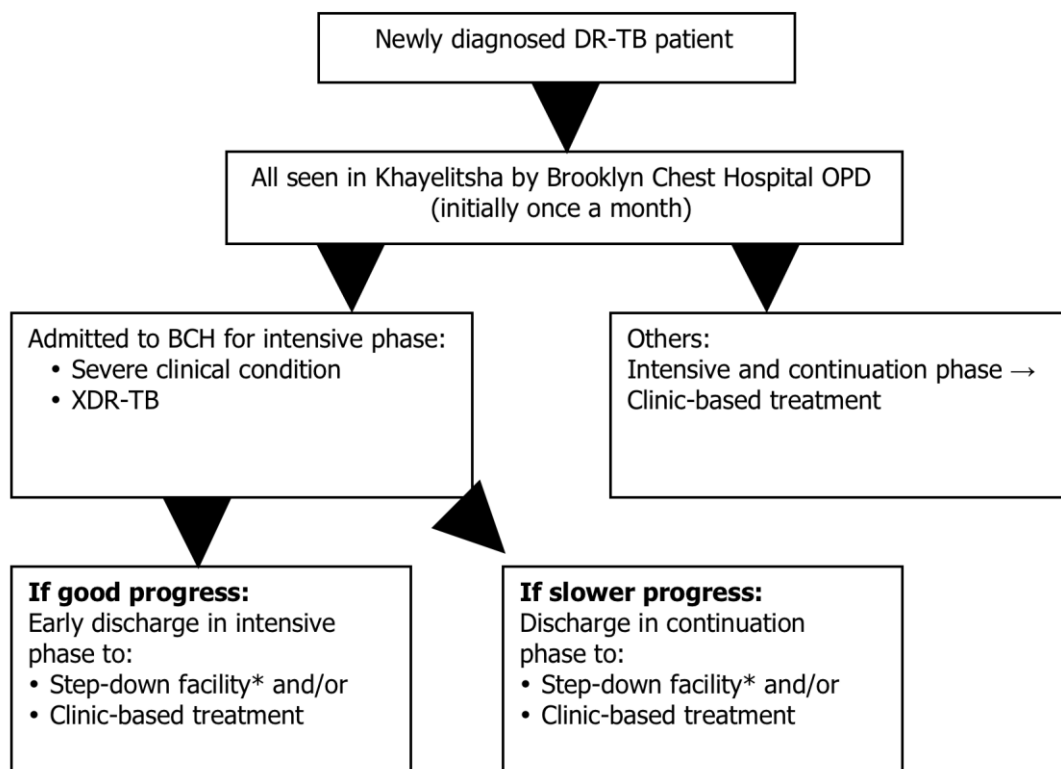
**Table 2.** VCT in TB services in Khayelitsha 2002-2007

## The Challenge of Drug-Resistant TB

Despite the high cure rate and success rates for TB treatment, increasing numbers of patients have been diagnosed with drug-resistant tuberculosis (DR-TB) in recent years, including multidrug-resistant (MDR-TB) and extensively drug-resistant tuberculosis (XDR-TB). In 2007, 154 MDR-TB and 11 XDR-TB cases were diagnosed in Khayelitsha.

The current national policy is to admit all MDR-TB cases to a dedicated MDR-TB treatment centre for at least six months. However, the high patient load in Khayelitsha has outstripped capacity at the local TB hospital (Brooklyn Chest Hospital), resulting in delayed treatment. Despite PGWC attempts to increase bed capacity it remains impossible to provide institutionalised care for so many people and for such prolonged periods of time. Furthermore, as over two-thirds of MDR-TB patients in Khayelitsha are co-infected with HIV, this centralised approach created contradictions with the primary health care-based decentralised ART programme, and often lead to patients feeling isolated and depressed, and in some cases absconding.

In response, a pilot project has been set up by MSF, PGWC, and the City Health Department to develop appropriate strategies for the provision of decentralised DR-TB care. Individualised adherence support mechanisms, defaulter tracing, improved infection control measures (in health facilities, patient's homes, and in the community), together with staff training in MDR-TB guidelines and large scale social mobilisation, are all key elements of the approach. In addition to improving capacity within Khayelitsha, this pilot project could establish strategies to help manage MDR-TB in similar settings elsewhere.



\* Lizo Nobanda: a step-down facility; scheduled to open in 2008

**Figure 7.** Step-down model for DR-TB in Khayelitsha

In Khayelitsha, all patients receive counselling from a dedicated MSF DR-TB counsellor upon diagnosis. The counsellor attends each clinic weekly to assist in monitoring patients for treatment adherence, and providing support to patients with difficulties adhering to treatment. Support groups have been established at clinics and counselling support is provided to Khayelitsha patients, including those hospitalised in Brooklyn Chest Hospital. To effectively monitor patients on treatment, each clinic keeps an DR-TB register, and data are entered in an electronic database.

As of September 2008, Brooklyn Chest Hospital will operate an MDR-TB outreach clinic in Khayelitsha. Only complex cases will be hospitalised: if patients are too ill to attend clinics daily or develop side effects to medications that require in-hospital monitoring. Patients infected with XDR-TB are also prioritised for hospitalisation.

Infection control assessments have been done for nine health clinics in Khayelitsha and feasible and cost-effective administrative and environmental changes recommended. Home-based infection control is part of the programme as experience to date has suggested that most homes can be made significantly safer simply through supporting patients and families in behaviour change and implementing basic infection control measures to increase ventilation. Systematic screening and monitoring of household contacts is done by a dedicated MSF TB nurse who also offers TB prophylaxis to family members.

Efforts are also underway to improve the standardised treatment regimen available for patients. It is anticipated that all the activities undertaken will result in improved treatment outcomes and ultimately in reduced community transmission of DR-TB.

## Antiretroviral Therapy

Since ART services were introduced in 2001, more than 10,000 people have been started on treatment at seven sites—Ubuntu clinic at Site B CHC, Nolungile CHC, Michael Mapongwana CHC, Mathew Goniwe, Kuyasa, Site C Youth Clinic, and most recently, Site B Youth Clinic. As of July 2008, 10,027 people have been initiated on ART, and 9,309 (93%) are remaining in care. Of these, 697 (7%) are children.

This section reviews ART needs, coverage, and NSP targets for Khayelitsha; evolution of the clinical profile of patients; long-term treatment outcomes; developments in decentralisation of ART; and ARV supply and distribution.

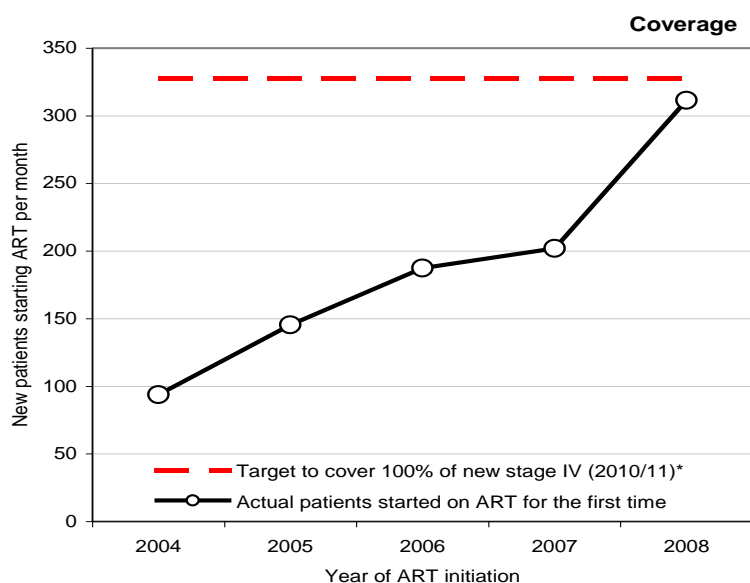
### ART Needs, Coverage & NSP Targets

Enrolment in 2006 and 2007 would have reached two-thirds of the revised provincial target of treating all patients with new stage IV disease based on the Actuarial Society of South Africa (ASSA) 2003 model. This denominator is indicative but differs from national guidelines for treatment eligibility (< 200 CD4 and stage IV); the Khayelitsha population is also underestimated (371,000 in 2001). It gives an indication though of monthly inclusion levels that need to be reached: an average of 330 patients should be started on treatment monthly in order to reach the minimum service levels set by the Province for the coming years, and 80% of this to meet the NSP minimum target.

<b>New patients</b>	2006	2007	2008	2009	2010
	2007	2008	2009	2010	2011
Enrolled	<b>2,122</b>	<b>2,322</b>			
Target (new stage IV)*	3217	3485	3708	3847	3929
	66%	67%			

\* Premised on Khayelitsha carrying 15.7% of the Provincial treatment burden, which may be an underestimate due to uncertainty in the size of the district population

**Table 3.** Enrolled patients on ART and coverage targets



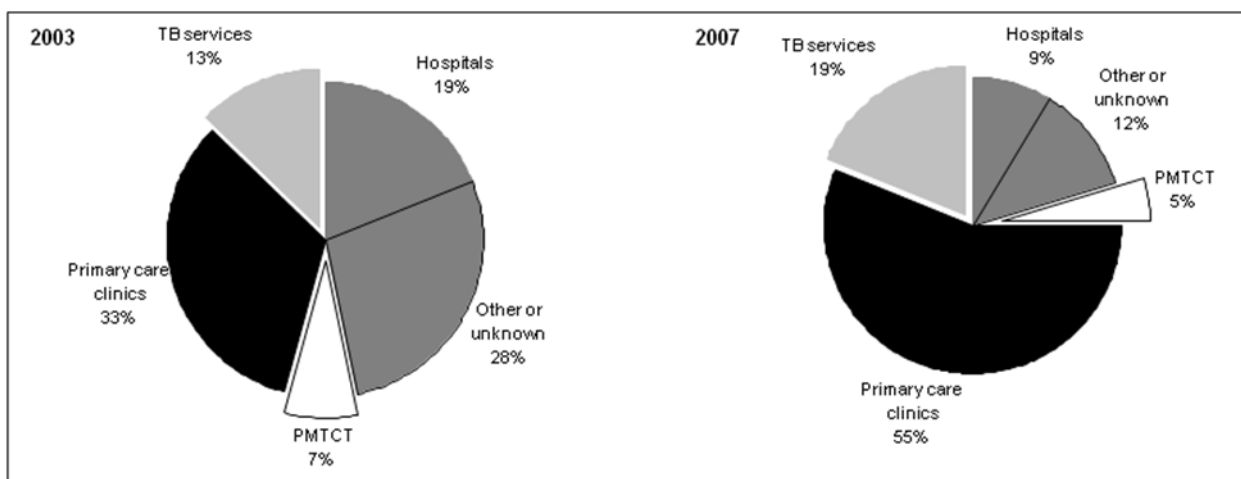
\* Premised on Khayelitsha carrying 15.7% of the Provincial treatment burden, which may be an underestimate due to uncertainty in the size of the district population

**Figure 8.** ARV enrolment in 3 Khayelitsha ARV units

<b>Total patients</b>	2006	2007	2008	2009	2010
<i>(end of period)</i>	2007	2008	2009	2010	2011
Remaining in care (RIC)			<b>9,309</b>		
Khayelitsha	5,546	7,234	9,393	11,555	13,514

**Table 4.** Remaining in care (RIC) targets (2008-2011)

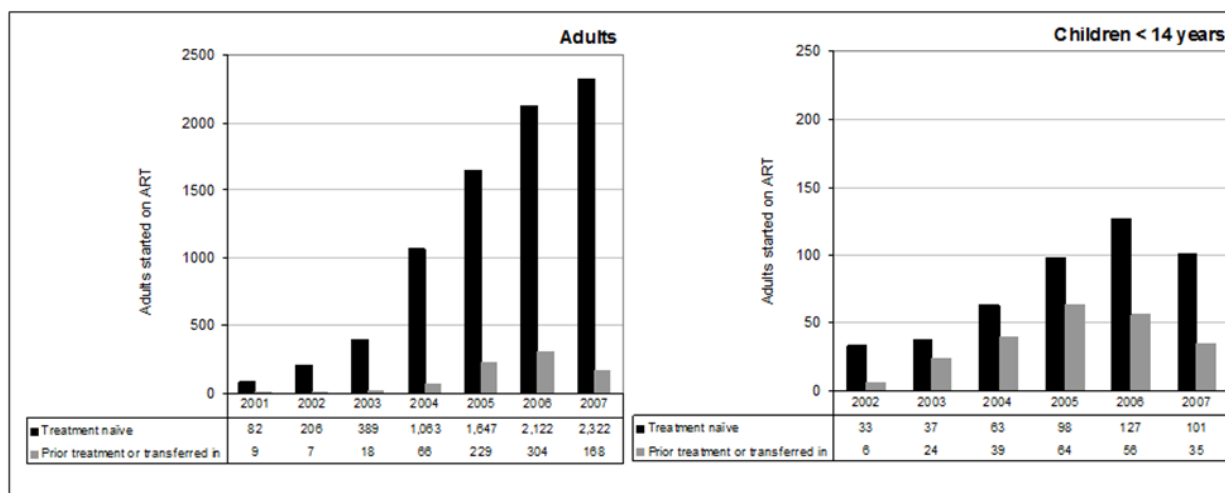
### Origin of Patients Referred to the ART Clinics



**Figure 9.** Origin of patients referred to ART clinics 2003 and 2007

The pattern of patient referrals for ART has changed significantly between 2003 and 2007 as a result of different strategies, including decentralisation of HIV care resulting in fewer referrals from central hospitals and increased referrals from City clinics; reduced role of the home-based care network in terms of referral (categorised under 'other or unknown' in the above charts); and routine testing in TB , PMTCT and STI services.

### Enrolment on ART (Adults & Children)

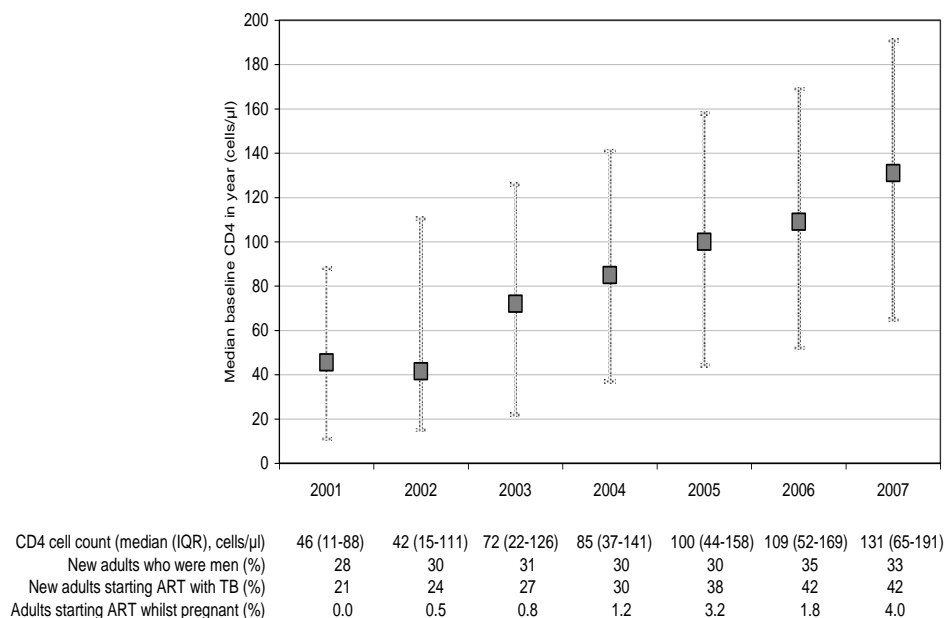


**Figure 10.** Adults and Children Enrolled on ART (2001-2007)

Adult ART enrolment rates continued to increase in 2007 with 2,322 new patients enrolled and a decrease in transfers-in, reflecting a decrease in patients being initiated at hospital level. There has been a sharp decline in enrolment of children from 127 in 2006 to 101 in 2007. This decline is mostly attributed to active recruitment by Tygerberg Hospital of all possible PCR (+) children for study purposes. The total number of children initiated on treatment as a proportion of the number of adults initiated, currently at 4.3% (101 out of 2,322) is down from 8.6% in 2005 as a result of this policy. This low total number of children initiated can also partly be explained by an effective PMTCT programme with a mother-to-child transmission rate that has been dropping since 1999 and is now estimated to be 3.5%.

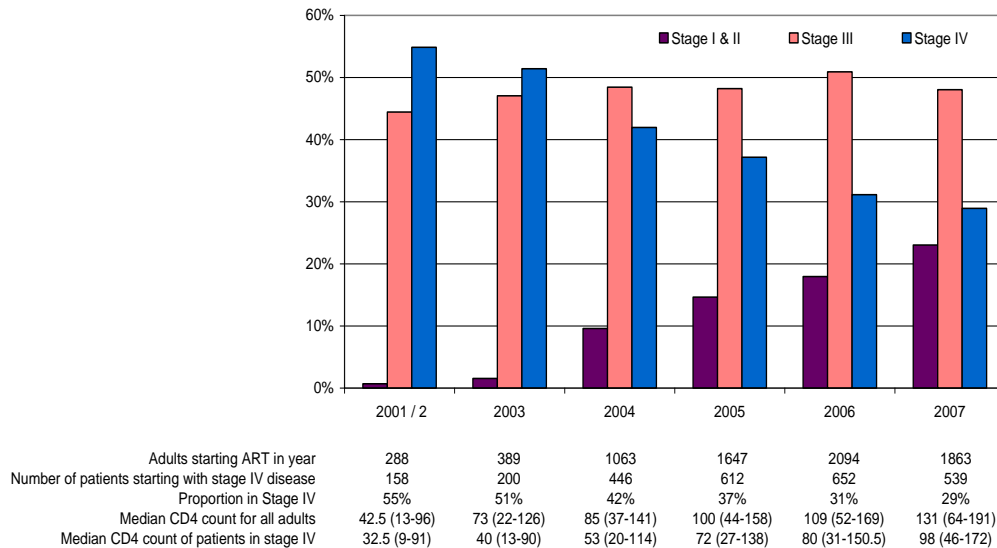
### Evolution of Baseline CD4

Scaling up of ART has allowed the programme to initiate people on treatment sooner. The baseline CD4 count of people starting treatment has increased from 48 in 2001 to 131 CD4/ $\mu$ l in 2007. This has helped to decrease early mortality and make patient management easier (people are less sick and experience fewer drug side-effects), in turn making nurse-based initiation easier.



**Figure 11.** Median CD4 count at baseline (2001-2007)

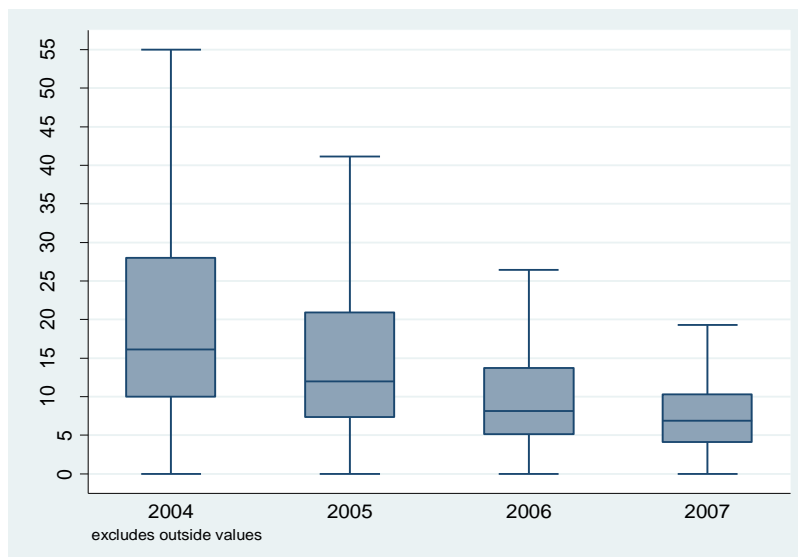
A similar impact is reflected in clinical stage of adults presenting for ART initiation with a steady decrease of the proportion of patients in stage IV (29% in 2007 from 51% in 2003). Stage IV patients present with a higher baseline CD4 count (98 in 2007 from 40 in 2003) and a parallel increase in initiation with clinical stage II.



**Figure 12.** Median baseline CD4 count and IQR by year

### Evolution of Patient Waiting Time Prior to ART Initiation

The median waiting time between first visit and treatment initiation for patients eligible for ART has been reduced from 16 weeks in 2003 to seven weeks in 2007. While this is still too long, it should translate into a major reduction of pre-treatment mortality. This high efficiency of enrolment suggests that clinics would be able to move towards an increase in CD4 threshold for patient initiation.



**Figure 13.** Time to initiation 2004-2007

### Long-Term Patient Outcomes

Long-term retention in care (RIC) shows 86.8% people alive and on ART at 12 months (NSP target 85%) and still remains high at 24 months at 81.5%. It drops to 73.7% after 48 months on ART. RIC at 12 months shows an improvement with time mainly due to a reduction of mortality linked to increased baseline median CD4 count. This trend does not continue at 24, 36,



and 48 months, due to an increase in the lost to follow-up (LTFU) rate across cohorts. This trend needs to be corrected in time with measures improving adherence together with a community-based defaulter tracing system, which has not existed to date in Khayelitsha (NSP target is 80% of defaulters traced by 2009), but which should be functioning by early 2009.

Remaining in care (%)	12 M	24 M	36 M	48 M
2001	83.4	81.2	78.0	73.8
2002	84.9	79.5	78.3	75.4
2003	86.4	81.7	77.3	73.5
2004	88.6	82.6	77.0	<b>74.2</b>
2005	87.8	82.6	<b>77.6</b>	
2006	88.3	<b>81.5</b>		
2007	<b>86.6</b>			
Remaining in care (RIC) = (total initiated) – (deaths + loss to follow-up)				

**Table 5.** Patients remaining in care 1-4 years on ART (average in bold)

Virological outcomes have remained quite good over time despite increasing numbers of patients, with approximately 90% of patients having an undetectable viral load at 12 months (above NSP targets) and approximately 87% at 18 months. Although this figure is based only on viral loads done, not taking into account in the denominator viral loads not done, these data suggest strong adherence despite an increased number of patients. Viral load data at 18 months include a small number of patients on second-line. The proportion of patients on second-line therapy has gone from 0.4% at 12 months to 6.5% at 36 months and 10.2% at 48 months on ART (2001-2006).

### Decentralisation of ART to City Clinics

While general HIV care had been decentralised successfully to all City clinics during 2006, a decision was made at the end of 2006 to also decentralise ART care, including treatment initiation. This decision was made with the aim of increasing access by bringing treatment closer to those in need, and spreading the workload across facilities in Khayelitsha. ART management was done by clinic nurses, supported by a doctor visiting twice a week. While the initial intention was to decentralise to all City clinics at once, only two (Matthew Goniwe and Kuyasa) have so far taken this on. Already, these two clinics are recruiting significant numbers of patients on ART (approximately 50-100 per quarter each), despite considerably less human resources.

Initial outcomes at six months show similar percentages of people "remaining in care" at the City clinics and the three CHCs: loss to follow-up is slightly lower in the City clinics whilst mortality is higher (see Table 6). The higher mortality is at least partially explained by the lower baseline CD4 counts in these two clinics, a known risk factor for mortality, and suggests that geographical proximity allows patients who previously were not accessing HIV care to be started on ART. The lower numbers of patients lost to follow-up in the City clinics could reflect the fact that smaller clinics are able to offer more patient-friendly services and foster better adherence. These observations need to be confirmed in further evaluations and analysis of long term outcomes.

	City Clinics		Large CHCs		
	Kuyasa	M Goniwe	Michael M	Nolungile	Ubuntu
<b>Enrolled</b>	42	79	166	142	176
<b>LTF</b>	<b>3 (7.1%)</b>	<b>4 (5.2%)</b>	17 (10.6%)	11 (7.8%)	13 (7.5%)
<b>Died</b>	<b>2 (4.8%)</b>	<b>7 (9.1%)</b>	2 (1.3%)	4 (2.8%)	8 (4.6%)
<b>RIC (%)</b>	37 (88.0%)	66 (86.0%)	141 (88.1%)	126 (89.4%)	152 (87.9%)
<b>TFO</b>	0	2	6	1	3

LTF = lost to follow-up; RIC = remaining in care; TFO = transferred out

**Table 6.** Six-month outcomes for Quarter 3 2007 (adults)

### **ARV Supply & Distribution**

Procurement of ARVs was handed over to the Provincial Government of the Western Cape in October 2004. Today, the only ARV drugs still supplied by MSF are the entero-coated formulation of didanosine (ddI) and tenofovir disoproxil fumarate (TDF); these were supplied to a limited number of patients under a Section 21 patient name-based exemption. Since TDF has now been accepted as part of the first-line regimen for specific indications (adverse reaction to d4T and AZT; Hepatitis B co-infection) by the Provincial guideline committee, supply will be taken over by provincial procurement. It will be important to ensure TDF is available more widely for first-line therapy, given its superior side effect profile, among other issues.

## **Adherence Support & Treatment Literacy**

In 2006, there were worrying indications of an increase in the number of treatment defaulters and loss to follow-up as well as a decrease in enrolment of new patients on ART. Services were saturated, staff turn over was high, staff morale was low, patients were frustrated by long waiting times, and the sheer volume of patients resulted in less contact time and counsellors doing patient preparation over fewer and shorter sessions. To meet enrolment targets and maintain an acceptable level of adherence, several novel steps were taken to streamline, adapt, and improve adherence support in Khayelitsha.

### **Adherence Clubs**

While people newly on ART are more likely to default than long-term patients who are "used to" their treatment, there is a challenge to maintain good adherence as people start to develop "pill fatigue" and struggle to continue to attend time-consuming clinic appointments. Recognising this, MSF established an "adherence club" approach to promote long-term disease management with special attention to treatment literacy and empowerment and to provide streamlined services for stable patients who require less frequent clinical consultations.

Adherence clubs are available for stable adult patients who have been on ART for over 18 months, with no complications and two consecutive undetectable viral loads results. The clubs are designed for clients at similar phases of treatment to help each other with long-term adherence issues such as treatment fatigue and reproductive health options as well as treatment literacy and psychosocial support. Clients receive a two or three-month supply of ARVs and a "reminder SMS" before their next appointment, and clinical appointments are streamlined for routine visits, freeing up time for clinicians to enrol new patients and focus on sicker clients.

The clubs are comprised of the same group of clients whose appointments have been harmonised, and sessions are modular and can theoretically be placed outside of the clinic to further reduce congestion. As of the end of July 2008, 760 clients have been recruited into 10 clubs. An evaluation is currently underway.

At Nolungile clinic in Site C, the ARV unit launched in 2008 fast track services for stable adults with good adherence on ART for four years or more (the duration on treatment will be reduced in the coming months). This service, the so-called "green clinic," and adherence clubs, with their special focus on treatment literacy, at Ubuntu are helping to adapt adherence support strategies for long-term patients while addressing quality concerns that can arise when services are overloaded.

### **Enhanced Facility & Community-Based Adherence Support**

ART clients in Khayelitsha represent one-third of the ART caseload for the Metro District Health Services. The high volume of patients, coupled with a recognition that adherence is weakest in patients newly initiated has led to a decision to launch an enhanced adherence model. The model developed in 2007-2008 will be implemented before the end of the year and will include the following:

- A cadre of 40 "Treatment Supporters" funded by the Provincial Department of Health assigned across the seven clinics providing ARV services for facility and community-based adherence support and defaulter-tracing
- A system of home visits and in-facility support groups designed to give patients additional support before starting ART and for people newly on ART
- Separation into high and low adherence risk "track" system, similar to that used in Gugulethu where high-risk patients are identified through certain criteria such as detectable

viral loads and receive additional support, via sessions with Adherence Counsellors, home visits and phone calls from Treatment Supporters

- An adherence screening for patients on ART presenting for routine visits using various tools
- A system for tracing defaulters on a timely basis via phone calls and home visits
- Education and support sessions to boost adherence for patients on ART at 6, 12, and 18 months
- Revised counselling modules and tools to improve patient preparation for ART

In 2007, MSF began an adherence forum to bring together adherence counsellors working for Lifeline (Site C and Site B), Wola Nani (Kuyasa and Matthew Goniwe), and Hope World Wide (Site C Youth). The monthly meeting allows for review of outcomes (including enrolment, loss to follow-up, etc.), enables counsellors to share experiences and receive training on new guidelines, and gives a platform for all parties to address gaps in support services.

## **Children & Youth**

The special needs of children and youth are increasingly being recognised in South Africa, particularly the specific needs of children who initiated treatment when very young and are entering adolescence. In May 2008, ART services were launched at the Site C Youth Clinic and adherence counsellors are being trained on providing support specific to youth. ART services at the Site B Youth Clinic started in August 2008. Some progress has been made, but much more needs to be done to provide adolescent-friendly services, including psycho-social support.

For children on ART, specific adherence support is provided to their carers, but more needs to be done to educate and support them directly as primary beneficiaries. In addition to other strategies, in the latter half of 2008, MSF and its partners plan on recruiting more children on ART into "Zip Zap"—a circus school programme for children, in place since 2005, to improve address the fact that "classical" support groups are not well-adapted for children.

## **Treatment Literacy**

TAC's long-running work in Khayelitsha emphasises rejection of discrimination, support of openness about HIV, community promotion of HIV prevention, VCT, and TB/HIV care and treatment, and empowerment of PLWHAs through treatment literacy and other strategies.

Treatment literacy efforts in Khayelitsha placed a growing emphasis on TB and TB/HIV in 2007-2008. Education sessions inside the clinic and during door-to-door campaigns in the community covered topics such as drug resistant TB (MDR and XDR), infection control, use of masks, TB treatment adherence and complexities of TB/HIV co-infection, such as difficulty diagnosing smear-negative TB in HIV-positive clients. In October 2007, a month-long TB awareness campaign was held to promote the use of TB masks in homes and clinics and to emphasise the importance of adherence and completion of TB treatment. These events were part of the build up to the Global TB March on 7<sup>th</sup> November 2007, which coincided with the World TB and Lung Conference, the annual meeting of the International Union Against Tuberculosis and Lung Disease, which was held in Cape Town.

## Conclusions

The HIV/AIDS care programme in Khayelitsha has been one of the most important in South Africa. As the first pilot ART programme in the public sector, it provided valuable early lessons on the effectiveness of delivering ART at the primary care level, acting as a catalyst for other programmes in the Western Cape and beyond. Today, after seven years of ARVs in Khayelitsha, over 10,000 people have been initiated on ART, with 93% alive and remaining in care, and the national NSP targets are being reached.

Several models of care have been developed in Khayelitsha that provide useful insights for other programmes. The integration of HIV and TB care, so essential in this environment where more than two-thirds of people with TB are HIV-positive, has been replicated in many other settings and is promoted by WHO as a model for best practice. The decentralisation of care to clinic level, with ART managed largely by nurses and supported by doctors, shows that this model of care promoted by the NSP is essential to further scale up treatment and promote patient retention by providing more proximal care: while there has been no increase in the number of doctors available for the programme since 2005, this nurse-based strategy has been promoted "de facto" but is still left without a proper regulatory framework.

Such operational research has also led to the development of a number of important clinical advances, including tools to support nurse diagnosis of smear-negative TB, the management of side-effects such as lactic acidosis using newer medicines, the use of viral load to promote adherence and detect drug resistance early, and the piloting, in South Africa, of more effective drug regimens for the treatment of MDR-TB.

However, a number of important challenges remain. There are too few children enrolled in the programme, and new ways need to be found to promote prevention and treatment in adolescents in particular. While quantitative targets of recruitment seem to be achievable with the support of new clinics, qualitative challenges of adherence and long-term retention in care need to be supported, including via new approaches to promote patient self-reliance and decongest services that are strained by an ever-growing cohort of patients on ART. The decentralised model of care relies on nurses who need to be adequately trained, remunerated, and supervised by doctors, and efforts are needed to ensure that both health cadres remain in the public sector, and in the country, in adequate numbers.

Finally, the rapid spread of MDR-TB and XDR-TB has created a significant clinical and public health challenge for which the best response is still not fully established. Currently, with hospital services overwhelmed by the growing number of M(X)DR-TB in the country, the Khayelitsha programme has taken on the challenge of piloting a model of decentralised MDR-TB care—one of just two sites in the country.

While the dedicated HIV services in Khayelitsha were launched with major support from MSF at the beginning, the Province and City have today taken over the core management of this programme, showing that continuity of ART services without the presence of an international NGO will be achievable. MSF's role is now to fill gaps where necessary and support service innovation, monitoring and evaluation, and operational research to overcome new clinical, programmatic, and policy challenges.

Thanks to this effective collaboration, which also involves academic and NGO partners, the Khayelitsha programme will continue to provide essential care for thousands of people while at the same time offering insights into some of the main challenges for HIV care in the long term.

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