Baseline assessment –South Africa Scaling up Programs to Reduce Human Rights-Related Barriers to HIV and TB services

November 2018 Geneva, Switzerland



DISCLAIMER

Towards the operationalisation of Strategic Objective 3(a) of the Global Fund Strategy, *Investing to End Epidemics*, 2017-2022, this paper was commissioned by the Global Fund to Fight AIDS, TB and Malaria and presents, as a working document for reflection and discussion with country stakeholders and technical partners, findings of research relevant to reducing human rights-related barriers to HIV and TB services and implementing a comprehensive programmatic response to such barriers in South Africa. The views expressed in the paper do not necessarily reflect the views of the Global Fund.

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LIST OF ACRONYMS

AIDS Acquired Immune Deficiency Syndrome
ARASA AIDS Rights Alliance of Southern Africa

ART Antiretroviral Treatment
ARV Antiretroviral medications

CAPRISA Centre for the AIDS Programme of Research in South Africa

CD4 Cluster of differentiation 4
CDA Central Drug Authority

CDC Centers for Disease Control and Prevention

COP Country Operational Plan

DBE Department of Basic Education

DCS Department of Correctional Services

DENOSA Democratic Nursing Association of South Africa

DOH Department of Health

DOJCD Department of Justice and Constitutional Development

DSD Department of Social Development

DR-TB Drug resistant TB
FSW Female sex workers

GFATM The Global Fund to Fight AIDS, Tuberculosis and Malaria
GIZ Deutsche Gesellschaft für Internationale Zusammenarbeit

HCW Health care workers

HIV Human immunodeficiency virus

HEARD Health Economics and AIDS Research Division

HEAIDS The Higher Education and Training HIV/AIDS Programme

HSRC Human Sciences Research Council

HTA High Transmission Area

HTS HIV testing services

IBBS Integrated bio-behavioural surveillance

IPV Intimate partner violence

I-TECH International Training and Education Center for Health

KIs Key informants

KIIs Key informant interviews
KPI Key performance indicator

KP REACH

Key Populations - Representation, Evidence and Advocacy for Change in

Health

LGBTI Lesbian, gay, bi-sexual, transgender, intersex

MDR-TB Multi drug resistant TB

MSM Men who have sex with men
MTB Mycobacterium tuberculosis

NACOSA Networking AIDS Communities of South Africa

NADCAO National Alliance for the Development of Community Advice Offices

NDMP National Drug Master Plan

NGO Non-governmental organisation

NSP National Strategic Plan

PEP Post-exposure prophylaxis

PEPFAR United States President's Emergency Plan for AIDS Relief

PLHIV People living with HIV

PMTCT Prevention of mother to child transmission

PR Principal recipient

PrEP Pre-exposure prophylaxis

PWID People who inject drugs

REAct Rights – Evidence – Action

RSA Republic of South Africa S&D Stigma and discrimination

Sugilia and discrimina

SA South Africa

SAHR South African Health Review

SAHRC South African Human Rights Commission
SALRC South African Law Reform Commission
SANAC South African National AIDS Council

SAPS South African Police Service

SGBV Sexual and gender-based violence

SOHACA Soweto HIV/AIDS Counsellors Association

SOGI Sexual orientation and gender identity

SR Sub-recipient

SRH Sexual and reproductive health

SRHR Sexual and reproductive health rights

STI Sexually transmitted infections

SWEAT Sex Worker Education and Advocacy Taskforce

TAC Treatment Action Campaign

TB Tuberculosis

TCC Thuthuzela Care Centre

UCSF University of California San Francisco

UKZN University of KwaZulu Natal

UNAIDS The Joint United Nationals Programme on HIV and AIDS

UNDP United Nations Development Programme

UNESCO United Nations Educational, Scientific and Cultural Organisation

UNFPA United Nations Population Fund

US\$ United States Dollar

USAID United States Agency for International Development

USG United States Government
UTT Universal test and treat

WHO World Health Organisation

WSW Women who have sex with women

XDR-TB Extensively drug resistant TB

Y+SA Youth Plus South Africa

TABLE OF CONTENTS

	onyms	
 Introdu Objecti 	uctionives and Expected Results	,
3. Method	dology	2
	eptual framework	
-	nd vulnerable populations included in the assessment	
	collection and analysis	
	gs for HIVen of HIV amongst key and vulnerable populations	
	ent trends in access and uptake of HIV services	
4.3. Overv	view of the law and policy context for address human rights barriers	12
4.3.1.	Legal framework for HIV-related human rights	12
4.3.2.	National strategies and plans	14
4.4. Huma	an rights barriers to HIV services	17
4.4.1.	Overview	17
4.4.2.	Stigma, discrimination and violence	17
4.4.3.	Stigma and discrimination in health services	20
4.4.4.	Punitive laws, policies and practices	24
4.4.5.	Challenges for adolescent girls and young women to access HIV serv	rices29
4.5. Effort	ts to address and remove barriers	34
4.5.1.	Overview	34
4.5.2.	Stigma and discrimination reduction	34
4.5.3.	Training of health care workers on human rights and medical ethics	40
4.5.4.	Sensitisation of law-makers and law enforcement agents	43
4.5.5.	Legal literacy	47
4.5.6.	HIV-related legal services	49
4.5.7.	Monitoring and reforming laws, regulations and policies	52
4.5.8.	Reducing discrimination against women in the context of HIV	55
4.6. Oppos	ortunities for scaling-up interventions	60
	gs for TBen of TB amongst key and vulnerable populations	
5.2. Trend	ds in service uptake for TB and TB/HIV services	63
5.3. Overv	view of law and policy context for TB-related human rights	64
5.3.1.	TB-related laws, policies and commitments	64
5.3.2.	National strategic plans	65
5.4. Huma	an rights barriers to TB services	66
5.4.1.	Stigma and discrimination	
5.4.2.	Punitive laws, policies and practices	
5.4.3.	Barriers related to gender	68
5.4.4.	Barriers related to poverty	69

5	5.4.5.	Harmful working conditions and exploitation7	0
5.5	. Efforts	to address and remove barriers7	0
5	5.5.1.	Overview	1
5	5.5.2.	Integrated approaches	1
5	5.5.3.	Reducing stigma and discrimination	'1
5	5.5.4.	Reduce gender-based inequity in the context of TB services	2
5	5.5.5.	Legal literacy7	3
5	5.5.6.	Monitoring and reforming laws and policies7	4
5	5.5.7.	TB-related legal services	5
5	5.5.8.	Sensitising law makers and law enforcement agents7	6
5	5.5.9.	Training of HCW workers on human rights and medical ethics7	6
5	5.5.10.	Mobilising and empowering TB patient and community groups7	7
5	5.5.11.	Improving access to TB services for people in prisons	7
		for Programmes to Remove Barriers to HIV and TB services 80 diture analysis for the HIV Investment Case	
6.2	. Externa	al funding for interventions to remove barriers	0
6.3	. Govern	ment investments in human rights programmes	31
		on of Funding Needs for Comprehensive Programmes8 ons8	
9. 1	Next Ste	ps8	6
		8omprehensive Programmes to Reduce Barriers to HIV Services9	
		omprehensive Programmes to Reduce Barriers to TB services 10	

EXECUTIVE SUMMARY

Introduction

This report documents the results of a baseline assessment carried out in South Africa to support its efforts to scale up programs to reduce human-rights-related barriers to HIV and TB services. Since the adoption of its new *Strategy 2017-2022: Investing to End Epidemics*, the Global Fund has joined with country stakeholders, technical partners and other donors in a major effort to expand investment in programmes to remove such barriers in national responses to HIV, TB and malaria (Global Fund, 2016a). While the Global Fund will support all countries to scale up programmes to remove barriers to HIV, TB and malaria services, it is providing intensive support in 20 countries in the context of its corporate Key Performance Indicator (KPI) 9: "Reduce human rights barriers to services: # countries with comprehensive programs aimed at reducing human rights barriers to services in operation (Global Fund, 2016b)." Based on criteria that included needs, opportunities, capacities and partnerships in the country, the Global Fund selected South Africa, with 19 other countries, for intensive support to scale up programmes to reduce barriers to services. This baseline assessment, focusing on HIV and TB, is a component of the package of support the country will receive.

The objectives of the baseline assessment were to:

- Identify the key human-rights-related barriers to HV and TB services in South Africa;
- Describe existing programmes to reduce such barriers;
- Indicate what a comprehensive response to existing barriers would comprise in terms of the types of programmes, their coverage and costs; and,
- Identify the opportunities to bring these to scale over the period of the Global Fund's 2017-2022 strategy.

The assessment took place between October and November 2017. It included a desk review, key informant interviews, and focus group discussions. It was conducted by the Health Economics and AIDS Research Division (HEARD) of the University of KwaZulu Natal under contract to the Global Fund.

The specific populations or groups included in the assessment as most affected by human-rights-related barriers were identified by taking into account epidemiological data; Global Fund criteria and guidance from the Stop TB Partnership (Global Fund, 2013; Global Fund, 2017b; Stop TB Partnership, 2015); and what South Africa's *National Strategic Plan for HIV*, *STIs and TB*, 2017-2022 (SANAC, 2017) identifies. The selection was further refined during an inception meeting convened by SANAC at the start of the assessment process. Based on this outcome, the populations that were included in the assessment are shown in the table below:

Key populations for HIV	Vulnerable populations for HIV	Key populations for TB
 Sex workers Gay men and other men who have sex with men (MSM) Transgender women People who use or inject drugs (PWID) Inmates People living with HIV (PLHIV) 	 Adolescent girls and young women Mobile and migrant populations (including undocumented migrants) Mineworkers Other LGBTI people 	 PLHIV Miners and peri-mining communities Inmates Health care workers PWID

While these are not the only population groups that are prioritised in the national HIV and TB responses in South Africa, they are those groups whose access to HIV or TB services is <u>most</u> affected by human rights concerns. The findings of the assessment in relation to these issues are summarised below in two main sections. Those for HIV are presented first, followed by those for TB.

Findings for HIV

South Africa continues to have one of the highest burdens of HIV globally. Although South Africa has a generalised HIV epidemic, available data indicates that prevalence rates are particularly high amongst key populations. Uptake of HIV services also varies. Using anti-retroviral treatment (ART) coverage as a proxy for service access, while, 2017, it was 60% for all PLHIV in the country (DOH, 2018), current coverage for the specific key and vulnerable populations included in the assessment was not known. Data from previous years suggested that, at least for sex workers, MSM, and prisoners, for example, in may have been lower than the national coverage rate at the time.

A number of human rights barriers affect this situation, with stigma and discrimination, particularly self-stigma, and stigmatising attitudes and practices on the part of health care workers (HCW) towards key populations, being amongst the most noteworthy. Punitive laws, policies and practices against sex workers and PWID, as well as socio-cultural norms that drive physical and sexual violence against key populations also negatively affect access to, uptake of and retention in services.

Finally, complex and intersecting challenges related to gender, many arising from negative socio-cultural norms about sexuality and sexual behaviour, particularly for adolescent girls and young women, both limit access to HIV and other sexual and reproductive health (SRH) services, including responses to sexual and gender-based violence (SGBV), and affect how such services are organised and provided.

To address these barriers, there are a number of interventions underway involving a range of governmental, non-governmental and private sector stakeholders, all operating within a generally favourable context for the protection and promotion of HIV-related human rights, with the exception of the punitive legal context for sex work and drug use. There is an increasingly

comprehensive law and policy framework that promotes gender equality and that aims to eliminate SGBV. However, the effectiveness of all of these efforts is hampered by poor implementation of laws and policies, and weak accountability mechanisms for the duty bearers responsible from them. They are also affected by poor coordination amongst stakeholders working on human rights priorities, and inadequate levels of funding to support interventions at an appropriate scale and scope, and for a substantive enough duration, to achieve sustained change. Despite this, the assessment found a number of best practices, particularly for community and population-specific interventions, that, together, can form the basis of a more comprehensive and longer-term effort to address and remove current barriers.

In order to comprehensively address human-rights-related barriers to HIV services in South Africa, the assessment identified that the following strategies, programmes and interventions should be developed and/or implemented.

PA1: Stigma and discrimination reduction

- Establish a national Stigma and Discrimination Reduction Working Group to develop a national Stigma and Discrimination Reduction Strategy. The Working Group should be a multi-stakeholder structure consisting of representatives of relevant government departments, key and vulnerable populations, senior religious and traditional leaders, communications experts, and academic experts on stigma and discrimination. The Strategy should contain, at a minimum, the elements described below.
- Develop a national stigma reduction communications campaign. The campaign should be evidence-informed and co-created with representatives of key and vulnerable populations. The campaign should use multiple modalities, and should deliver new messages in new ways. There are useful lessons to be learnt by the communications work done over the past three years as part of the Global Fund-supported, regional KP REACH project.
- Scale up interventions which support anti-stigma champions. Two levels of champions must be created: 1) a small group of high profile leaders and celebrities to participate in the communications campaign; and 2) a larger group of community-level, traditional and religious leaders with a focus on rural areas where stigma is more entrenched.
- Strengthen the technical and operational capacities of key-population-led and PLHIV networks to deliver integrated programmes to address stigma, discrimination and violence against their members at community level. The assessment encountered a number of community-led entities working to implement these types of activities but struggling with inadequate technical and operational capacity to scale up and sustain their efforts.
- Scale up the Community Anti-stigma Programme to an additional ten districts, taking into account learning from the current effort. The ten new districts should be selected in consultation with key stakeholders and target additional areas of the country where HIV stigma and discrimination remains elevated.
- Strengthen psychosocial support programmes to address self-stigma for PLHIV and key populations in communities. This should be done by 1) creating

posts for professional counsellors at organisations providing services; and 2) equipping a cadre of peer educators with advances skills in counselling and support.

- Strengthen the High Transmission Area programme to ensure that it can fulfill its mandate to reach key populations with HIV prevention services. This should include provision of technical support to review its model so that it is more aligned with best-practice approaches that are tailored for the current South African epidemiological and social-cultural context, and that integrate strategies to reduce stigma and discrimination.
- Support rapid assessments, surveys and evaluations to inform stigma reduction interventions. This should include repeating the PLHIV Stigma Index Survey but with changes to the design and participant recruitment strategy so that it can also measure stigma and discrimination towards PLHIV who are members of key populations.
- Conduct a national situational assessment on access to HIV services for foreign migrants and develop an action plan to address the results. The assessment should include foreign migrants who are members of key populations, especially LGBTI and sex workers. While this assessment has made some tentative conclusions that serious human rights barriers to services exist for these groups, more comprehensive information is needed on an urgent basis

PA 2: Training for HCW on human rights and medical ethics

- Scale up the implementation of the Health Workers for Change training to cover more health facilities. The Department of Health (DOH) with the Democratic Nursing Association of South Africa (DENOSA) should lead this effort. The Regional Training Centres can be used to deliver the training. Non-clinical staff in facilities should be included in such trainings.
- Deliver key population sensitization training (using the I-TECH manual) through the Regional Training Centres to improve coordination of this work and to ensure country-wide coverage.
- Equip key-population-led civil society organisations (CSOs) with the technical and operational capacities to provide district-level sensitization training and mentorship for health facilities. There should be two types of interventions in this regard: 1) a year-long mentorship and engagement with a health facility leading to a form of accreditation as a key-population- friendly service point; or 2) periodic sensitization workshops and active local engagement where a one-year approach is not feasible (modeled on the approach of the Sex Worker Education and Advocacy Taskforce (SWEAT), for example).
- Strengthen and scale up local collaborations between health facilities and CSOs, especially those that are key-population-led, for programme components such as outreach, screening and referrals, peer navigation, or adherence support. Such partnerships can improve HCWs attitudes and commitment to providing stigma-free services. Such partnerships can be a logical outcome of the collaborative approaches described in the previous activity.

- Review training curricula for all health and social services professions to assess whether they are adequately supporting the development of competencies in diversity, sexuality, gender and human rights. Based in the results of the review, develop a national action plan to address gaps.
- Scale up provision of Critical Diversity Literacy training to staff in relevant departments of universities, colleges and other health training institutions. This can prompt departments themselves to review their training programmes and can also prepare the way for needed curriculum changes once they are identified.

PA 3: Sensitisation of law-makers and law enforcement agents

- Undertake a focused assessment on the role of the judiciary and traditional leaders in potentially contributing to barriers to services for key populations and develop an action plan to address the results. The assessment should reach into communities where there is more reliance on traditional justice and conflict mediation.
- Support South SANAC to take a lead role to improve senior-level coordination and cooperation between itself, South African Police Service (SAPS), DOH, CSOs and other relevant stakeholders in order to strengthen the role of the police in communities in reducing barriers to HIV services. This work could include encouraging SAPS to issue a public commitment to ceasing the practice of confiscating condoms from sex workers, or harm reduction commodities from PWID.
- Scale up efforts to bring about positive shifts in knowledge, attitudes and practices of the police regarding key and vulnerable populations and their need for HIV services. In doing this, ensure that sensitization efforts are strategically targeted for sustainability and optimal impact. This includes working towards institutional shifts through more comprehensive, longer-term approaches, while at the same time continuing local-level interventions with individual policing units.
- Continue work to train and sensitise policy-makers, police and the judiciary on the importance of harm reduction for PWID. Balance the emphasis in this work between harm reduction as an HIV prevention intervention, and harm reduction as globally-endorsed human right for all drug users. Also, ensure that there is continued emphasis on the evidence that shows that harm reduction does not encourage drug use.
- Strengthen the operational and technical capacity of local key-population-led CSOs to facilitate and lead 'constructive engagement' interventions with local police as well as local traditional leaders. While a number of CSOs already do this work they are not sufficiently funded to sustain their efforts long enough to secure permanent change.
- Expedite the establishment of a National Policing Board, as mandated in the National Development Plan. According to the plan, one of the objectives of the National Policing Board should be, "to develop a professional code of ethics and analyse the

professional standing of policing, based on international norms and standards."

PA 4: Legal literacy

- Support PLHIV networks and key-population-led CSOs to scale up activities
 to improve knowledge regarding HIV-related human rights for individuals in
 their respective communities. It is at the local community level where these gaps in
 knowledge continue to occur.
- Develop standardized legal literacy materials targeting the different key and vulnerable populations that need them. There should be standard educational tools, such as those developed by SWEAT for sex workers, for LGBT, PWID, or migrants, for example.
- Ensure that paralegals and other similar types of individuals working in CSOs, such as the National Alliance for the Development of Community Advice Offices (NADCAO), have full knowledge and can provide assistance regarding HIV-related legal and human rights. This should include strengthening skills to assist PLHIV and other individuals from key populations to access justice and redress when their rights are infringed.
- Strengthen the civic education outreach programmes of Legal Aid South Africa, and the Department of Justice and Constitutional Development (DOJCD). This is needed to ensure that they reach and provide rights education to the most marginalised, stigmatised and vulnerable populations highlighted in this report.

PA 5: HIV-related legal services

- Establish a national mechanism for the consolidation, auditing and analysis of HIV-related human rights violations towards PLHIV and other key and vulnerable populations. SANAC with SAHRC should take a leadership role in this regard, but must develop the mechanism with full consultation with PLHIV and key populations constituencies. The mechanism should include an on-line platform for human rights monitoring and case management.
- Scale up the REAct model to more provinces to support the national monitoring mechanism. This includes providing sufficient technical and operational capacity to local PLHIV and key-population-led CSOs to undertake community mobilization, reporting and verification activities.
- Extend and subsequently promote the role of Legal Aid South Africa to provide legal support and representation to all people (including key population constituencies, not only PLHIV) who have experienced HIV-related legal or human rights challenges and who qualify for services. This will include strengthening the technical capacity of Legal Aid to respond to human rights challenges faced by key and vulnerable populations. It will also include expanding its community outreach function to ensure that members of key and vulnerable populations in local communities are aware of the services it can provide.

- Provide increased financial and technical support to NADCAO members so that Community Advice Offices and their paralegals can undertake outreach, and can reach more PLHIV and other individuals from key and vulnerable populations with their services. This important resource is currently very underutilised by individuals in communities who need such services.
- Provide a cadre of peer educators working with key populations in local communities with training and support to work as human rights defenders or paralegals. These would involve existing peer educators who are already well-connected with key population groups and who can assist with information, mediation and dispute resolution, or can refer and accompany individuals to entities like Legal Aid South Africa, Equality Courts or Community Advice Offices. The SWEAT model can be built on for such training.

PA 6: Monitoring laws, regulations and policies

- **Develop and implement a national HIV and TB Human Rights Accountability Scorecard.** SANAC and the SAHRC should collaborate to lead this effort with the full buy-in of civil society constituencies. Sufficient technical and operational support should be provided to fast-track this initiative.
- Sustain the collective effort to revise the provisions in *Sexual Offences Act* regarding sex work. This should include promoting consultation between government, primarily the DOJCD, civil society and sex worker representatives. The consultations must take full account of the most robust and recent evidence regarding, for example, the significant reduction in the HIV-related vulnerabilities of sex workers, and the improvements in access, uptake and retention in HIV treatment and other services, that can come about as a result of decriminalization.
- Promote consultation and collaboration between government and civil society to advance drug-related laws and policies which are evidence-based and reduce harms against drug users, including harms related to HIV. This work should include sustaining the Drug Policy Week initiative as an important opportunity for such consultation and collaboration to occur.
- Provide sufficient technical and operational support to the CDA so that it fulfills its mandate of coordinating drug use response efforts in South Africa. The strengthening of technical capacity should have as a priority topics and actions related to advancing the harm reduction approach.
- Increase the technical and operational capacity of more key-population-led networks and organisations to participate in policy-making processes and to be more effective at lobbying and advocacy. The sex worker networks are the most developed in this regard. Work is needed with more LGBT groups and with PWID constituencies to also be more prominent, active and well-coordinated in national law and policy-making processes.

- Complete the development of the NSP for GBV. Sufficient technical and operational support should be provided to the Department of Women in the Office of the Presidency to lead this effort. Civil society actors should find ways to bring about a *rapprochement* with the Department as this work proceeds.
- Sustain support for strategic litigation. This has become an effective tool for securing the accountability of 'duty bearers', whether in the public or private sectors, for promoting or protecting HIV-related human rights and for removing barriers to services.

PA 7: Reducing discrimination against adolescent girls and young women in the context of HIV

- Strengthen and sustain the TCCs. This should be done on the basis of a comprehensive review and the development of a multi-year plan that incorporates lessons learnt and that emphasises efficiency and sustainability. The review should pay special attention to what local CSOs contribute and how to strengthen and maintain this component of the model.
- Roll-out other community-based, well-coordinated models to support survivors of SGBV and other forms of physical violence that can be implemented in areas where there are no TCCs. Other approaches are needed besides TCCs given the scale of the challenge that remains in South Africa.
- Critically evaluate the components of combination HIV interventions for adolescent girls and young women that address removing barriers to access, uptake and retention across the continuum of HIV interventions (including adherence to PEP, and PMTCT, for example). Based on the results, develop modifications to programme designs to improve this component where required.
- Sustain interventions involving government and civil society partners to remove barriers for adolescents and young people to access and remain in HIV services. This includes the components of AYFHS; working with adolescents and young people themselves to be resilient to stigma and discrimination in health services and to demand more accountability for change; and, working with communities to take ownership of the health and well-being of young people. Specific attention should be paid to adolescents living with HIV in all their diversity.
- Empower more adolescent girls and young women to be advocates and community mobilisers regarding ending violence and other harmful cultural practices that limit or deny their SRHR. CSOs in communities should coordinate this work and ensure that effective mechanisms are in place for the safety and protection of these individuals.
- Provide additional training and support to a cadre of peer educators to be able to recognise and respond to individuals in local communities who are victims of gender-based violence but are reluctant to seek support. This should include equipping the CSOs implementing peer outreach programmes to provide effective referrals and to accompany clients, as well as to continue to support peer educators themselves to address their own psychosocial needs.

- Sustain and scale-up interventions that provide comprehensive support to individuals from key populations that experience gender-based violence in all its forms. SWEAT, Sisonke and others have developed effective models that should be expanded to all key population groups, for example.
- Ensure that programmes training HCWs workers on the health needs of key populations include sufficient content on providing medical and psychological support to individuals who have experienced gender-based violence. While this may already be part of the ANOVA model, for example, it was not clear from the assessment whether it was being comprehensively addressed through the joint I-TECH and DOH training programme.

Opportunities for scaling-up interventions

The preceding sections have outlined what is feasible in South Africa, in terms of the considerable organisational and technical resources which exist within the national HIV response, to reduce or remove human rights barriers to HIV services. The NSP, with its cross-cutting approach to human rights concerns, can serve as the 'blue print' for these efforts. However, for these commitments to move from concept to action, some particular challenges need to be addressed in terms of leadership, accountability and coordination:

- SANAC should provide an effective leadership and coordination mechanism for the implementation of the comprehensive response outlined in this report. In this regard, the role of the Law and Human Rights Sector Working Group should be reviewed to determine whether or not in its current form it can fulfil the leadership and coordination role on behalf of SANAC.
- Similarly, key population constituencies should develop a national mechanism for leader-ship and coordination of work to address human rights barriers. While there are many strong individual entities, their work is not yet effectively coordinated. Implementing the comprehensive response will require that this gap be addressed. As coordinated constituencies they will have a stronger and more effective presence within the SANAC-led coordination structure described above.
- SANAC and civil society constituencies need to engage government stakeholders more effectively on removing barriers given how most HIV and TB services are delivered through the public sector. This could be done through the SANAC-led coordination structure.
- How funding programmes are structure and delivered, including for Global Fund, should be critically reviewed to ensure that work in communities to address human rights barriers is adequately resourced and that the number of intermediary organisations is reduced. SANAC should consider, for example, supporting specific organisations with high technical competency and constituency credibility to manage and deliver funding for human rights interventions.
- Finally, across the comprehensive response, a stronger emphasis should be place on evaluation, learning and continuous improvement for the design and delivery of interventions to remove barriers.

Findings for TB

South Africa has one of the highest TB burdens globally, a trend that is in large part driven by a very high level of HIV/TB co-infection. Findings from this assessment indicate that, while TB services are delivered country-wide, for certain populations--particularly prisoners, some mineworkers, farm-workers and migrants--significant challenges remain. Access to TB services continues to be inhibited by:

- Community-level stigma and misunderstandings about the disease;
- Stigmatising attitudes and practices against certain groups, particularly PWID, on the part of HCW; complex structural and organisational challenges within prisons;
- Gaps in systems and accountabilities for workplace health and safety measures to reduce TB risk, and limited access to justice and redress for those who contract TB as a result; and,
- Challenges to provide TB services in rural and remote areas, particularly for farm workers.

While there are a number of efforts underway to address and resolve these challenges, progress is slow in some areas, particularly with regard to prisons. There are, nevertheless, opportunities to improve these efforts through more comprehensive and longer-term strategies to address and remove barriers. They include the following:

PA 1: Reducing TB-related stigma and discrimination

- Sustain country-wide programmes to raise awareness about TB and to reduce stigma and discrimination. This work should become more 'granular', however, to reach deeper into communities.
- Sustain and expand interventions that mobilise communities to understand and reduce stigma and discrimination. More financial and technical resource are needed at the 'ground level' where stigmatizing attitudes and practices regarding people with TB in communities continue to occur.
- Develop a multi-year action plan to reduce stigma and discrimination. The plan will ensure that work by different stakeholders in different sectors to address TB stigma in a more consolidated and coordinated. The plan will also provide the means for tracking progress.
- As part of the action plan, put in place a national coordinating mechanism for TB stigma reduction. For stigma and discrimination reduction efforts to have more impact, a national coordinating mechanism is critical.
- Scale-up interventions to address dual stigma. Counselling materials and approaches should be reviewed to ensure that they can assist co-infected individuals with managing self-stigma.
- Scale-up qualitative research on TB and TB/HIV stigma, particularly self-stigma. The enduring nature of community and personal level stigma is still not fully understood in South Africa. Additional qualitative research is needed to ensure that interventions to address stigma are evidence-informed and properly oriented.

PA 2: Reducing gender-based inequity in the context of TB services

- Scale-up up efforts in communities to improve access to social support for TB-affected households, including for disability grants. Many of the poorest, TB-affected households are not yet accessing such support.
- Strengthen advocacy work for mining communities to ensure that mining companies support households of TB-affected miners. The burden of caring for sick miners primarily falls on women in these communities who are not consistently included in workplace programmes that support their spouses or partners.

PA 3: Legal literacy

- Sustain and expand community-level activities to promote human rights literacy in the context of TB, particularly for issues of privacy, confidentiality and autonomy. This should include using standard tools and scaling-up community level dissemination of materials.
- Continue to include TB-related human rights components in communitybased rights literacy programmes for HIV. This is essential in the context of South Africa's high rate of HIV/TB co-infection.
- Increase the capacity of community-based entities to promote TB human rights literacy. A number of community-based groups are contracted to assist with community mobilization activities for TB awareness, TB screening, DOTS and contract tracing. All of these groups should have a high level of competence to also promote TB human rights literacy.

PA 4: Monitoring and reforming laws and policies

- Sustain efforts by civil society to monitor human rights trends in the context of TB. This includes information gathering in communities as well as media and advocacy campaigns.
- Sustain support for strategic litigation. As with issues related to HIV, strategic litigation has become an effective tool for securing the accountability of 'duty bearers', whether in the public or private sectors, for promoting or protecting TB-related human rights.
- Support additional participatory action and operational research, and pilot programmes for new approaches to TB care that empower patients and respect their privacy and confidentiality. The current 'top down' disease management approach, with DOTS and contract tracing, deters individuals from seeking diagnosis and treatment, particularly men.
- Support civil society to monitor the implementation of the new public health regulations, particularly the aspect of mandatory measures.

PA 5: TB-related legal services

Provide training or technical support, where needed, to ensure that legal service providers (mentioned under HIV, above) can address TB-specific legal concerns. Such concerns will include access to compensation and other benefits, unfair employment practices, and discrimination in communities, amongst others.

PA 6: Sensitising law makers and law enforcement agents

- Integrate content related to TB in the sensitisation and engagement activities with law enforcement agents and others, described under HIV, above.
- Sustain civil society advocacy for proper judicial oversight of prison conditions. As part of this work, ensure that TB-specific issues are part of the oversight process.

PA 7: Training of HCW workers on human rights and medical ethics

- Review training curricula and training processes to ensure that content on TB-related human rights is included and that it receives enough emphasis in training programmes. The should the review identify gaps, the DOH should take the lead to address them.
- Scale up work by civil society to improve accountability and action on the part
 of DOH at national and provincial levels for safe working conditions for
 HCWs. As a first step, the work of entities like TAC and TB Proof in this regard should be
 sustained.
- Address TB-related stigma amongst HCWs as part of the multi-year action plan described above. Specific, focused efforts are needed, led by the DOH, to ensure that HCWs who acquire TB disease can be promptly diagnosed and treated in safe and confidential environments.

PA 8: Mobilising and empowering TB patient and community groups

Sustain and expand community-level efforts to support and empower people living with TB to challenge and overcome stigma. This should include TB-specific support groups where needed, as well as support for people living with or recovered from TB to work as spokespersons and community mobilisers

PA 9: Improving access to TB services for people in prisons

- Support NGOs to scale-up sensitization and TB literacy trainings with DCS members and inmates to improve facility-level mobilization, collaboration and support for TB control in prisons. Current efforts in this regard do not cover all facilities.
- Strengthen coordination mechanisms between the DCS and other government departments (such as the DOH and SAPS) and stakeholders (NGOs) to improve the effectiveness and impact of TB interventions within prisons.
- Provide HCWs in prisons with full occupational health support to reduce their risk of TB exposure and to support them with full benefits should they acquire TB disease.

- Scale up programmes led by former prisoners that support newly released peers to transition back to communities. These programmes should include counselling and support for stigma reduction and that ensure linkages to health facilities for TB and HIV care.
- Scale-up parolee and civil-society-led advocacy for prison reform with a priority on improving basic conditions in prisons for reduction of TB and other
 health risks. The full engagement of former prisoners as advocates and spokespersons
 within current efforts is an important gap that should be addressed.

Opportunities for scaling-up interventions

As with the national response to HIV, the NSP is also the 'blueprint' for the national TB response. The NSP structures also provide opportunities for greater collaboration and integration across the HIV and TB domains for efforts to remove barriers. Such collaboration would also ensure that the wealth of organisational, intellectual, social and economic capital which exists within the national HIV response is equally engaged to address TB-related priorities. Some specific issues should be addressed as efforts to strengthen and scale up efforts to remove barriers to TB services proceed:

- The considerable data gaps for current, comprehensive information on the burden of TB for key populations, as well as on trends in access and uptake of TB and TB/HIV services for these groups, should be closed. Without this data, the extent of current barriers and their impacts cannot be fully comprehended which, in turn, inhibits how interventions to address barriers can be planned, implemented and evaluated.
- There should be greater collaboration between CSOs working on TB-related rights and responsibilities with the prison reform movement as such a combined effort will potentially have greater effectiveness in achieving comprehensive change, particularly with respect to the structural and underlying conditions within prisons that fuel the ongoing epidemic of TB in these settings.
- SANAC should clarify and strengthen its role as the coordinator of human rights actions
 to address barriers to TB services. For many stakeholders, this role is currently not clear,
 and this lack of clarity should be resolved.

Funding for programmes to address and remove barriers to HIV and TB services

To gather data on the amount of funding for programmes to address and remove human rights -related barriers to HIV and TB services in South Africa, a desk review and analysis of existing data sets were conducted, as well as new data collection and key informant interviews. Tables A, below, shows the results for HIV.

Table A: Total HIV funding by programme area and year (2016-2017)

Programme Area	Funds for 2016	Funds for 2017	Total (US\$)	%
	(US\$)	(US\$)	(5.54)	

Stigma and discrimination reduction for key populations	933 514	2 320 638	3 254 152	16%
Training for HCW on human rights and medical ethics related to HIV	499 462	477 331	976 793	5%
Sensitization of law-makers and law enforcement agents	48 967	136 457	185 424	1%
Legal literacy ("know your rights")	10 414	13 886	24 300	ο%
HIV-related legal services	306 881	1 127 627	1 434 508	7%
Reducing discrimination against women in the context of HIV	6 732 314	7 587 873	14 320 187	71%
TOTAL HIV	8 531 552	11 663 812	20 195 364	100%

Funding for HIV-related stigma reduction programmes supported targeted activities for key populations, and for adolescents and young people, using a variety of delivery modalities. Funding for the reduction of discrimination against women in the context of HIV supported prevention programming for adolescent girls and young women in and out of school and in tertiary institutions, as well as SGBV programmes, including advocacy activities.

Table B, below, shows funding levels for TB for each year by programme area.

Table B: Total TB funding by programme area and year (2016-2017)

Programme Area	Funds for 2016 (US\$)	Funds for 2017 (US\$)	Total (US\$)	%
Stigma and discrimination reduction for TB	473 552	440 567	914 119	61%
TB programs in prisons and other closed settings	546 245	36 450	582 695	39%
TOTAL TB	1 019 797	477 017	1 496 814	100%

Funding for TB programmes supported stigma reduction in mines, mining communities and informal settlements, and combination prevention programming in prisons.

The data collected for the assessment also showed where this funding came from. **Table C**, below, illustrates these results for HIV.

Table C: Funding for HIV by source and year (2016-2017)

Funder	Funds for 2016 (US\$)	Funds for 2017 (US\$)	Total (US\$)	%
Aidsfonds	114 388	211 188	325 576	2%
Comic Relief	124 649	137 770	262 420	1%
European Union	-	277 428	277 428	1%
Global Fund	5 083 894	6 502 570	11 586 464	57%
OSISA/ SANAC	1 050 812	-	1 050 812	5%
United States Government	2 743 357	3 216 930	5 960 287	29%
Mixed	597 075	412 782	1 009 857	5%
TOTAL	9 714 176	10 758 668	20 472 843	100%

As shown in the table, USG/PEPFAR and the Global Fund contributed 86% of the identified funding in both years. The amount of US\$11 586 464 under Global Fund includes US\$1 496 814 for TB programmes. The analysis captured four other sources of funding. Response rates from key informants for this component of the baseline assessment were low, meaning that there are likely more sources that have not yet been identified. Even if these data were available, however, it is most likely that the predominance of USG/PEPFAR and Global Fund sources would remain.

Overall, what the data reveal is that the amount of current or potential resources available to support programmes to address human rights barriers to HIV and TB is substantive, amounting to at least US\$20 million in 2017 from external sources alone. However, the largest proportion of these funds support combination HIV programmes for adolescent girls and young women which are broad in scope and, although they contain components address human rights or gender-related barriers for these groups, the amount of resources attached to them could not be determined. As a result, this may lead to an over-estimation of current human rights investments from external sources.

With regard to domestic investments, national and provincial level budgets for HIV and TB do not disaggregate budget lines according to the human rights programme categories and although there are government investments in human rights programming to remove barriers, these could not be specifically identified. In the end, the funding analysis shows that there appears to be a degree of fragmentation amongst external funders, government departments and implementers in the different sectors, including the civil society sector. As this assessment has highlighted, current efforts to address barriers are hampered by the lack of an overall, nationally coordinated approach, and this no doubt affects how such efforts are funded.

Projection of funding needs for comprehensive programmes to address and remove barriers to HIV and TB services

The final component of the assessment was to estimate the five-year cost of implementing the comprehensive approach. A high-level summary for HIV is shown in **Table C**, below.

Table C: Estimated funding needs for HIV 2017-2021 (US\$)

Human rights and stigma Pro- gramme	Year 1	Year 2	Year 3	Year 4	Year 5	Total	%
PA 1. Stigma and discrimi- nation reduc- tion for key populations	1 714 403	1 373 551	1 234 341	1 701 982	1 084 377	7 108 654	24%
PA 2. Training for health care workers (HCW) on human rights and medical ethics related to HIV	410 088	215 336	169 951	202 724	93 056	1 091 154	4%
PA 3. Sensitization of law- makers and law enforce- ment agents	469 812	316 434	304 981	400 104	287 037	1 778 368	6%
PA 4. Legal literacy ("know your rights")	293 225	272 464	265 543	265 543	265 543	1 362 318	5%

Grand Total	6 408 376	5 970 237	5 629 100	5 845 486	5 676 639	29 529 839	100%
Other activities (evaluation and research)	183 <i>7</i> 81	591 189	647 971	497 061	870 193	2 790 195	9%
PA 7. Reducing discrimination against women in the context of HIV	786 <u>5</u> 94	734 806	596 617	423 782	722 142	3 263 940	11%
PA 6. Monitoring and reforming laws, regulations and policies relating to	739 861	1 721 343 745 116	745 116	704 604	704 604	3 639 301	12%
PA 5. HIV-re- lated legal services	1 810 612	1 701 949	1 664 581	1 649 687	1 649 687	8 495 910	29%

Given the analysis, above, of available funding to support programmes to remove barriers to HIV services, it appears that, should this level of investment be sustained, South Africa is highly likely to be able to mobilise sufficient resources to implement the five year comprehensive programme.

A high-level summary for TB is shown in **Table D**, below.

Table D: Estimated funding needs for TB 2017-2021 (US\$)

Programme	Year 1	Year 2	Year 3	Year 4	Year 5	TOTAL	%
Area							
PA 1: Reduc- ing stigma and discrimi- nation							
	570 320	526 809	421 584	345 988	345 988	2 210 689	20%
PA 2: Reducing gender-related barriers to TB services							
	107 664	140 006	140 006	140 006	140 006	667 688	6%
PA 3: TB-re- lated legal ser-							-0/
vices	30 691	15 346	6 138	6 138	6 138	64 451	1%

PA 4: Moni-							
toring and re-							
forming poli-							
cies, regula-							
tions and laws							
that impede							
TB services							
	151 000	151 000	151 000	151 000	151 000	756 001	7%
PA 5: Know	151 200	151 200	151 200	151 200	151 200	756 001	
your TB-re-							
lated rights							1%
	42 320	33 437	24 553	24 553	24 553	149 416	170
PA 6: Sensiti-							
zation of law-							
makers, judi-							
cial officials							
and law en-							
forcement							
agents							
							6%
	143 042	125 274	143 042	125 274	125 274	661 907	370
PA 7: Training				_			
of health care							
workers on							
human rights							
and ethics re-							
lated to TB							
	199 798	164 263	164 263	326 017	148 343	1 002 684	9%
PA 8: Ensur-	,,,,			<u> </u>	1 010		
ing confiden-							
tiality and pri-							
vacy						0 (1%
	22 097	9 040	9 040	9 040	9 040	58 256	
PA 9: Mobiliz-							
ing and em-							
powering pa-							
tient and com-							
munity groups							
	212 210	336 979	336 979	336 979	336 979	1 560 127	14%
PA 10: Pro-	_	33 - 777	55- 7/7	55- 7/7	33-7/7	3 /	
grams in pris-							
ons and other							
closed settings							
,							23%
	404 617	575 436	554 462	554 462	550 018	2 638 996	_0,0
Other activi-							
ties (evalua-							
tion and re-							
search)	380 397	140 066	455 289	251 177	233 067	1 459 996	13%
Grand Total	= 277				,		100
	0.064.056	0.015.055	0.406 ===	0.050.905	0.050.605	11 000 010	%
	2 264 356	2 217 855	2 406 557	2 270 835	2 070 607	11 230 210	

As the assessment identified a much lower investment in current programmes to reduce human rights barriers to TB services, South Africa will have some distance to cover to mobilise

sufficient resources to implement that five-year comprehensive programme. However, the catalytic investment available to the country under the 2018-2020 funding cycle will at least provide a starting point for being able to leverage additional resources from both domestic and external sources.

1. INTRODUCTION

This report documents the results of a baseline assessment carried out in South Africa to support its efforts to scale up programmes to reduce human rights barriers to HIV and TB services. Since the adoption of its new *Strategy 2017-2022: Investing to End Epidemics*, the Global Fund has joined with country stakeholders, technical partners and other donors in a major effort to expand investment in programs to remove such barriers in national responses to HIV, TB and malaria (Global Fund, 2016a). This effort is grounded in Strategic Objective 3 which commits the Global Fund to: "introduce and scale up programs that remove human rights barriers to accessing HIV, TB and malaria services;" and, to "scale-up programs to support women and girls, including programs to advance sexual and reproductive health and rights and investing to reduce health inequities, including gender-related disparities." The Global Fund has recognised that programmes to remove human rights barriers are an essential means by which to increase the effectiveness of Global Fund grants as they help to ensure that health services reach those most affected by the three diseases. The Global Fund is working closely with countries, UNAIDS, WHO, UNDP, Stop TB, PEPFAR and other bilateral agencies and donors to operationalise this Strategic Objective.

Though the Global Fund will support all countries to scale up programmes to remove barriers to services, it is providing intensive support in 20 countries in the context of its corporate Key Performance Indicator (KPI) 9: "Reduce human rights barriers to services: # countries with comprehensive programs aimed at reducing human rights barriers to services in operation (Global Fund, 2016b)." This KPI measures, "the extent to which comprehensive programs are established to reduce human rights barriers to access with a focus on 15-20 priority countries." Based on criteria that included needs, opportunities, capacities and partnerships in the country, the Global Fund selected South Africa, with 19 other countries, for intensive support to scale up programmes to reduce barriers to services. This baseline assessment, focusing on HIV and TB, is a component of the package of support the country will receive.

2. OBJECTIVES AND EXPECTED RESULTS

The objectives of the baseline assessment were to:

- Identify the key human rights barriers to HV and TB services in South Africa;
- Describe existing programmes to reduce such barriers;
- Indicate what a comprehensive response to existing barriers would comprise in terms of the types of programmes, their coverage and costs; and,
- Identify the opportunities to bring these to scale over the period of the Global Fund's 2017-2022 strategy.

Overall, the results of the assessment are meant to provide a baseline of the situation as of 2017 in South Africa. This effort will be followed up by similar assessments at mid- (2019) and end-points (2022) of the Global Fund's strategy in order to capture the impact of the scale-up of programmes to remove barriers in South Africa and in the other countries included in the intensive support initiative.

3. METHODOLOGY

The assessment was conducted between October and December 2017, according to the following methodology.

3.1. Conceptual framework

The conceptual framework that guided the baseline assessment was as follows:

- In South Africa, as in other countries regionally and globally, there exist human rights barriers to the full access to, uptake of and retention in HIV and TB services.
- These barriers are experienced by certain key and vulnerable populations who are more vulnerable to and affected by HIV and TB than other groups in the general population.
- There are human rights programme areas comprising several interventions and activities that are effective in removing these barriers (UNAIDS 2012).
- If these interventions and activities are funded, implemented and taken to sufficient scale in the country, they will remove or at least significantly reduce these barriers.
- The removal of these barriers will increase access to, uptake of and retention in HIV and TB services, and thereby accelerate country progress towards national, regional and global targets to significantly reduce or bring to an end the HIV and TB epidemics.
- These efforts to remove barriers will also protect and enhance Global Fund investments, strengthen health systems and strengthen community systems.

The main categories of human rights barriers to HIV and TB services that the assessment addressed were (Global Fund, 2017a, b; Timberlake, 2017):

- Stigma and discrimination, including within the provision of health care services;
- Punitive laws, policies, and practices;
- Barriers arising from HIV-or-TB-related discrimination based on gender;
- Poverty and socio-economic inequality; and,
- Harmful working conditions and exploitation (mainly for TB).

UNAIDS, the Global Fund, and the Stop TB Partnership have identified the following main programmatic approaches to address and remove barriers (UNAIDS, 2012; Global Fund, 2017a,b; Stop TB Partnership, 2015):

Stigma and discrimination reduction;

- Training for health care providers on human rights and medical ethics;
- Sensitisation of law-makers and law enforcement agents;
- Legal literacy ("know your rights");
- HIV or TB-related legal services;
- Monitoring and reforming laws, regulations and policies relating to HIV and TB; and,
- Reducing discrimination against women in the context of HIV and TB.

For TB, some additional components were included:

- Ensuring confidentiality and privacy related to TB diagnosis and treatment;
- Mobilising and empowering TB patient and community groups;
- Addressing overly-broad policies regarding involuntary isolation or detention for failure to adhere to TB treatment; and,
- Making efforts to remove barriers to TB services in prisons.

These programmatic approaches can either be adapted as focused interventions or included as components of broader HIV or TB programmes. The assessment describes which approaches predominate in South Africa and how, given current barriers to HIV and TB services, they contribute to removing such barriers for the specific populations or groups that are most affected by them.

3.2. Key and vulnerable populations included in the assessment

The specific populations or groups included in the assessment as most affected by human rights barriers were identified by taking into account:

- Global Fund and Stop TB Partnership criteria for identifying key and vulnerable populations for HIV and TB (Global Fund, 2013; Global Fund, 2017b; Stop TB Partnership, 2015); and,
- The key and vulnerable populations identified in South Africa's *National Strategic Plan for HIV, STIs and TB, 2017-2022* (SANAC, 2017).

Further clarification was provided during an inception meeting hosted by the South African National AIDS Council (SANAC) in October 2017 and attended by key stakeholders. The final list of populations included in the assessment is shown in **Table 1**, below.

Table 1: Key and vulnerable populations for HIV and TB included in the assessment

Key populations for HIV	Vulnerable populations for HIV	Key populations for TB
 Sex workers Gay men and other men who have sex with men (MSM) Transgender women People who use or inject drugs (PWID) Inmates People living with HIV (PLHIV) 	 Adolescent girls and young women Mobile and migrant populations (including undocumented migrants) Mineworkers Other LGBTI people 	 PLHIV Miners and peri-mining communities Inmates Health care workers Migrant workers (including farm workers) PWID

These are not the only population groups that are prioritised through the national HIV and TB responses in South Africa. They are, however, those groups whose needs for HIV or TB services are the greatest and whose access to these services is <u>most</u> affected by human rights concerns.

3.3. Data collection and analysis

Data collection involved the following main steps:

- Desk review--A comprehensive desk review was conducted of sources describing the context for HIV and TB in South Africa; sub-populations and groups most affected by the two diseases; human rights barriers to HIV and TB services for these groups; and the country's efforts to address and remove these barriers. Sources for the review included peer-reviewed publications, national documents (plans, policies, strategies and progress reports), and other documents produced by the different stakeholders involved in efforts to address and remove barriers.
- Development of fieldwork priorities and the fieldwork plan--Based on the results of the desk review, specific priorities for further data collection were defined. The desk review identified that barriers to HIV and TB services were for the most part well documented. This allowed the fieldwork to focus more on current efforts to address those barriers, including assessing their effectiveness and identifying potential best-practice approaches for scaling up, and on recommendations from stakeholders on how to achieve a more comprehensive approach that would ultimately remove as many barriers as possible. The fieldwork plan included key informant interviews (KIIs), round-table discussions, and focus group discussions (FGDs) with a full range of multi-sectoral partners, PLHIV, and representatives of other key or vulnerable population groups. It also included data collection in the four largest metropolitan areas (Johannesburg, Cape Town, Durban and Pretoria), as well as sites in the provinces of Mpumalanga, Free State, Eastern Cape, KwaZulu Natal (KZN) and Limpopo.
- **In-country data collection**--Data collection took place between November and December, 2017. It was conducted primarily in English, although some fieldworkers were proficient in local languages (for example, isiZulu, isiXhosa, seSotho, seTswana) and conducted interviews in them when necessary. Support to launch the data collection process was

provided through SANAC, which also established an Advisory Committee, comprised of government, civil society and development partners, to support the assessment process.

Overall, 153 key informants representing 86 entities participated in the assessment. This included 9 national and provincial government entities, 3 international non-governmental organisations (NGOs), 50 national and local civil society organisations (CSOs), 8 academic institutions, 1 private sector organisation, 4 donors, and 6 UN agencies and technical partners. In addition, FGDs were convened with representatives from key or vulnerable populations, including: PLHIV; people living with TB; gay men and other MSM; sex workers; PWID; transgender; and older adolescent and young women, including those living with HIV.

Data analysis involved mainly thematic analysis of documents and interview notes according to the key themes and concepts set out in the conceptual framework.

The assessment was conducted by a consultancy team led by a lead researcher from the Health Economics and AIDS Research Division (HEARD) of the University of KwaZulu Natal (UKZN) and twelve other local consultants and experts. Ethics clearance was provided by the Biomedical Research Ethics Committee at UKZN.

In the sections that follow, the assessment findings are presented in two main sections. HIV is first, followed by TB.

4. FINDINGS FOR HIV

The findings for HIV are presented below in the following sequence: an overview of the HIV epidemic in South Africa, with specific attention to the key and vulnerable populations included in the assessment; information on trends in access to and uptake of HIV services to illustrate the extent of current gaps for these groups; an overview of the general context for the HIV response with a particular focus on the components addressing human rights; an analysis of human rights barriers to HIV services; an analysis of current efforts to address barriers, including gaps, challenges, and recommended actions to achieve a more comprehensive approach; and, finally, an analysis of opportunities for scaling up current efforts over a five-year period.

The findings describe how South Africa continues to have one of the highest burdens of HIV globally. Although the country has a generalised HIV epidemic, available data indicates that prevalence rates are particularly high amongst key populations, although comprehensive, current data to demonstrate this are not available for all groups. Uptake of HIV services also varies. Using ART coverage as a proxy for service access, while, in 2017, it was 60% for all PLHIV in the country, specific data for the key and vulnerable populations included in this assessment were not available. Data from earlier years, for sex workers, MSM, and prisoners, for example, suggested that coverage for these groups was lower than the national rate.

A number of human rights barriers affect this trend with stigma and discrimination, particularly self-stigma, and stigmatising attitudes and practices on the part of health care workers (HCW), being amongst the most important. Punitive laws, policies and practices against sex workers and PWID, as well as socio-cultural norms that drive physical and sexual violence against key populations, also negatively affect access to services.

Complex and intersecting challenges related to gender, many arising from negative socio-cultural norms about sexuality and sexual behaviour, particularly for adolescent girls and young women, both limit access to HIV and other sexual and reproductive health (SRH) services, including responses to sexual and gender-based violence (SGBV), and affect how such services are organised and provided.

To address the above barriers, there are a large number of interventions underway involving a range of government, non-governmental and private stakeholders, all operating within a generally favourable context for the protection and promotion of HIV-related human rights. There is also an increasingly comprehensive law and policy framework that promotes gender equality and that aims to eliminate SGBV (with the exception of the punitive legal context for certain key populations noted above).

However, the effectiveness of all of these efforts is hampered by inadequate implementation of laws and policies, and weak accountability mechanisms for the duty bearers responsible for them. They are also affected by poor coordination amongst stakeholders working on human rights priorities; and, inadequate levels of funding to support interventions at an appropriate scale and scope, and for a substantive enough duration, to achieve sustained change. Despite this, the assessment found a number of best practices, particularly for community and population-specific interventions, that, together, can form the basis of a more comprehensive and longer-term effort to address and remove current barriers.

The sections that follow provide the more detailed analysis of these trends and issues beginning with data regarding the burden of HIV disease across the different key and vulnerable populations that are the focus of this assessment.

4.1. Burden of HIV amongst key and vulnerable populations

Data on the burden of the HIV epidemic on key and vulnerable populations are not complete or comprehensive for each group, nor are they current in a number of cases. After outlining the general characteristics of the HIV epidemic in South Africa, in terms of gender, age and location, these data are described in this section and, for the most part, reveal that the key and vulnerable populations included in the assessment carry a disproportionately higher burden HIV disease than others not in these groups.

In 2016, population-wide HIV prevalence (0-49 years) was estimated at 12.9% (Statistics South Africa, 2016; UNAIDS, 2016).¹ HIV prevalence for adults (15-49 years) was estimated at 18.9% but with significant variation by age and sex. It was 22.3% for adult women and 14.2% for adult men. HIV incidence was estimated at 1.27% in 2016, amounting to 270,000 new HIV infections of which 100,000, or 37%, occurred amongst adolescent girls and young women (15-24 years), and 12,000 or 4.4% amongst children (0-14 years). In the same year, there were 110,000 AIDS-related deaths for all ages. Finally, there were an estimated 7 million adults and children living with HIV in the country, 58% of which were adult females. There were also an estimated 1.7 million orphans as a result of HIV.

More detailed data on epidemiological trends are from 2012 only (Shisana et al., 2014). They showed significant variations in HIV burden by age, sex and location for that year. The distribution of HIV prevalence by age and sex is shown in **Figure 1**, below:

¹ All data in this paragraph is taken from these sources unless otherwise indicated.

Males Females 45 36.0 31.6 40 28.8 28.0 35 25.6 HIV prevalence (%) 30 25 17.4 17.3 15.8 20 15 10 5 25-29 30-34 35-39 60+

Figure 1: HIV prevalence by age and sex in 2012

Source: Shisana et al., 2014.

In 2012, HIV prevalence was significantly higher for females (15 years and older) than for males across all age bands. The differences were greatest for the 15-19 and 20-24-year age bands and are discussed in greater detail below (all from Shisana et al., 2014).

Age group (years)

The distribution of HIV prevalence by province is shown in **Figure 2**, below.

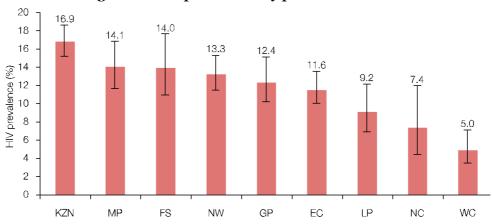


Figure 2: HIV prevalence by province in 2012

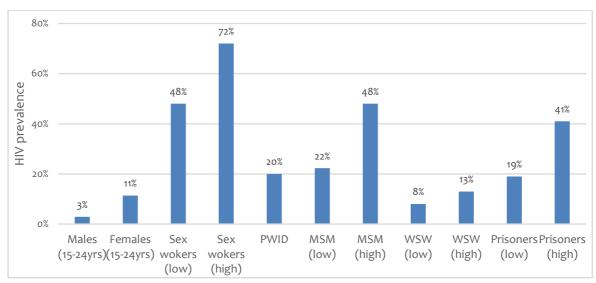
Key: KZN – KwaZulu-Natal, MP – Mpumalanga, FS – Free State, NW – North West, GP – Gauteng, EC – Eastern Cape, LP – Limpopo, NC – Northern Cape, WC – Western Cape

Source: Shisana et al., 2014.

HIV prevalence was highest in KZN and lowest in Western Cape. Available HIV prevalence data for the specific key or vulnerable population groups included in this assessment are summarised in **Figure 3**, below.

Figure 3: HIV prevalence by key and vulnerable population groups²

² Sources: Males and females, 15-24 years (Shisana et al., 2014); Sex workers (UCSF et al., 2015); PWID (Scheibe et al., 2016; MSM (Cloete et al., 2014); WSW (SANAC, 2016b); Prisoners (Scheibe et al., 2011)



WSW=women having sex with women

These data come from different time periods and study methodologies and therefore cannot be compared between groups. The data are described in more detail below.

Adolescents and young people--In 2012, HIV prevalence was estimated to be 11.4% for females and 2.9% for males aged 15-24 years (Shisana et al., 2014). The data also showed significant differences in the rates between 15-19-year-olds and 20-24-year-olds. HIV prevalence amongst 15-19-year-old girls was 5.6% and 17.4% amongst 20-24-yea-old women. It was 0.7% and 5.1%, respectively for adolescent boys and young men. Since 2012, numerous studies have confirmed this trend of an expanding HIV sub-epidemic amongst adolescent girls and young women (Closson et al., 2016; Fatti et al., 2014; Hargreaves et al., 2016; Maskew et al., 2016).

Sex workers-The Sex Worker Education and Advocacy Taskforce (SWEAT) conducted a rapid size estimation study in 2013 which indicated that there were approximately 153,000 sex workers, of whom 138,000 were female, 7,000 were male and 6,000 were transgender (SWEAT, 2013). More recent data estimated the sex worker population size as being between 185,257 and 205,240 sex workers (including 39,064-45,772 male sex workers) in South Africa (Setswe et al., 2015).

The integrated bio-behavioural surveillance (IBBS) survey, conducted in Johannesburg, Cape Town and Durban in 2014, found the following (UCSF et al., 2015):

- A wide variation in HIV prevalence amongst women working in different urban centres: 71.8% in Johannesburg; 39.7% in Cape Town; and 53.5% in Durban; and,
- A higher HIV prevalence amongst women who were 25 years and older compared to those in the 16-24-year age band (for example, 79% versus 59% in Johannesburg).

Another IBBS, also published in 2015, surveyed 173 female sex workers and 518 long-distance truck drivers (LDTD) along the N3 highway in KZN and Free State provinces (UCSF and ANOVA, 2015). It found an HIV prevalence rate of 88.4% amongst the female sex workers

sampled (and a prevalence of 16.7% amongst the LDTD). Both studies demonstrate the overwhelming high HIV prevalence amongst the sex worker population, a trend that is in part fuelled by a number of the barriers identified by this assessment. There are no specific data, however, about HIV prevalence amongst male or transgender sex workers.

PWID--A study in five South African cities found that HIV prevalence amongst people who inject drugs was 14% (18% among females and 13% among males) (Scheibe et al., 2016). A quarter of participants reported symptoms of a sexually transmitted infection (STI) in the previous 12 months, and 22% had ever worked as a sex worker (51% of females). The gender-disaggregated size estimates for PWIDs are between 41,374 and 44,135 for men, and 31,489 and 34,402 for women (Setswe et al., 2015).

Gay, bisexual and other MSM--There is no current, country-wide estimate of HIV prevalence. Studies conducted in different parts of the country indicate a wide variation in findings that are not necessarily comparable. For example, the Marang Men's Project IBBS survey, conducted in 2013, found HIV prevalence rates of 22.3% in Cape Town, 48.2% in Durban, and 26.8% in Johannesburg (Cloete et al, 2014). In 2015, the results of an MSM HIV data triangulation study (assessing all research on MSM since 2008) indicated that there was a "concentrated HIV epidemic amongst MSM in South Africa" but with no consensus on HIV prevalence rates (Department of Health [DOH] and SANAC, 2015).

For **other lesbian**, **bisexual**, **transgender or intersex (LBTI) populations**, SANAC (2016a) outlines the very limited information available on HIV prevalence in lesbian and transgender populations (there are no prevalence data for intersex persons). It states that HIV prevalence amongst **women who have sex with women** (WSW) is estimated to be between 8% and 13%. It has also been reported that nearly 50% of WSW also have consensual heterosexual sex, and 19% engage in transactional sex. Finally, as the most serious indication of HIV risk for this group, studies indicate that as many as 31% -45% of WSW in different locations in the country have experienced coerced sex or rape.

The first baseline estimate for South Africa's **transgendered** community found the number of transgender women in South Africa to be 72,156, and transgender men to be 67,510 (Setswe et al., 2015). The are no HIV prevalence data for this population; however, the first IBBS study for this population was underway at the time assessment was conducted.

For **prisoners**, the Department of Correctional Services (DCS) reported HIV prevalence among inmates to be 19.8% in 2006 and 22.8% in 2009 (DCS, 2010). There are no more recent estimates. These rates were based on programme data and not an HIV prevalence survey. Modelled prevalence estimates using these data give a range between 19% -41% depending on facility and location (Scheibe et al., 2011).

Finally, with regard to other vulnerable populations, no information was found on HIV prevalence **for migrants** and/or **undocumented foreigners**, although the multiple structural drivers of HIV have been described amongst this population (Vearey et al., 2011).

The range of HIV prevalence data, despite its limitations, in showing the high burden of HIV across key and vulnerable populations, also indicates the level of need for access to HIV services. What is currently known (and not known) about this for these groups is described below.

4.2. Current trends in access and uptake of HIV services

For the most part, comprehensive, disaggregated data on current access to and uptake of HIV services for all key and vulnerable populations for HIV are not available. This therefore makes it challenging to determine a baseline trend against which to measure improvement. What the available data do indicate, however, using uptake of ART as a proxy for uptake of other HIV services, is that the situation continues to improve in South Africa although, as the limited data suggest, at a slower rate for some key population groups.

PLHIV: The most recent data from the DOH indicates that, by April 2018, there were 4 000 562 million PLHIV of all ages on ART, or 60% of the entire population of PLHIV in the country (DOH, 2018).

Adolescent girls and young women: There are no current disaggregated data on uptake of HIV services for adolescent girls and young women. In 2012, only 14% of 15-24-year-old PLHIV were on ART (Shisana et al., 2014). A systemic literature review reported relatively low treatment adherence rates at only 65% for this group (Zanoni et al., 2016).

Sex workers: The *South African National Sex Worker Plan 2016-2019* (SANAC, 2016b) records that sex worker programmes had reached 35,000 to 40,000 individuals by 2016 (or 23%-26% coverage of the estimated population of 153,000). These programmes include peer education; condom and lubricant distribution; behaviour change communication; HIV testing services (HTS); linkage to HIV treatment; social mobilisation; and, counselling interventions in relation to stigma and discrimination, experiences of violence, and for drug use.

More detailed data on uptake of services come from 2012 and showed an overall low trend in use of HIV services (approximately 50%) with the lowest being for ART (all from UCSF et al., 2015):

- Overall, nearly half of the female sex workers (FSW) participants had sought health care in the previous year (54% in Johannesburg; 36% in Cape Town; and 59% in Durban);
- Just over half had tested for HIV in the previous year (46% in Johannesburg; 71% in Cape Town; and 51% in Durban);
- Of those testing HIV-positive in the study, less than half were previously aware of this based on their self-reported HIV status through the survey instrument (51% in Johannesburg; 25% in Cape Town; and 29.5% in Durban); and,
- A low proportion of FSW who had been previously diagnosed HIV-positive were on ART (23% in Johannesburg; 45% in Cape Town; and 36% in Durban);

More recent data on these trends were included in the evaluation of the Phase II of the Global Fund-supported National Sex Worker Programme, which operated from 2013-2016 (Networking HIV and AIDS Communities of South Africa [NACOSA], 2016). The study collected interviews from 1699 participants across 22 sites in nine provinces and found that 54% of sex workers reported using state health facilities. However, information on use of HIV services was not included.

There are no data on trends in HIV service uptake for male or transgender sex workers. However, SWEAT has established support groups for these individuals, called Siyasebenza and Sistazhood, respectively, which, in addition to peer support, provide referrals for HTS and other HIV services (KII with SWEAT, November 2017).

PWID: The review found no comprehensive data on access or uptake of HIV services for PWID. In 2015, TB/HIV Care Association started the StepUP Project, which uses mobile clinics and outreach teams to provide sterile needles, HTS, and "hygiene commodities" to PWID in 3 cities: Cape Town, Durban and Pretoria (TB/HIV Care Association, 2016; Williams et al., 2015). Within the first year of operation, the project had reached more than 2,000 clients, conducted 826 HIV testing sessions, and had distributed over 381,000 sterile needles (TB/HIV Care Association, 2016). Although opioid substitution therapy (OST) for drug dependency treatment is allowed in South Africa, it is currently provided only through private facilities or as part a small public-sector pilot project in Durban (Cole, 2016; Williams et al., 2015).

MSM: The Marang study found that over 80% of MSM surveyed in the three cities included in the study had been tested for HIV; the majority (61%-72%) had had an HIV test in the previous 12 months (Cloete et al., 2014). Respondents were most likely to have been tested at a gay-friendly health centre, followed by a public health facility. Using data generated from a number of studies, Scheibe et al. (2017b) recently attempted to estimate the HIV treatment cascade for gay, bisexual and other MSM in South Africa. The results are shown in **Figure 4**, below:

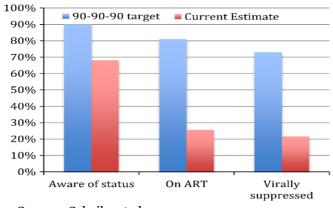


Figure 4: HIV cascade for gay, bisexual and other MSM

Source: Scheibe et al., 2017.

The study estimated that 68% of the population of MSM who were PLHIV were aware of their status. Of that group, only 38% were on ART and, of those, 84% were virally suppressed.

Transgender: No data were found for this group on uptake of HIV services, a gap that, as already noted, was being addressed as the assessment was being conducted.

Prisoners: In 2016, the Department of Correctional Services (DCS) reported that 199,750 prisoners had been tested for HIV and knew their status (DCS, 2016; there are no more current reports). Furthermore, it state that 21,722 of the 22,142 prisoners who tested positive for HIV were on antiretroviral therapy, a rate of 98%. In sharing these results, the DCS acknowledged the assistance of its NGO partners (Aurum Institute, TB/HIV Care Association, and Right to

Care) which played a substantive role in achieving these results. As an example of the most recent improvements, Right to Care indicated that a Universal Test and Treat (UTT) programme (treatment initiation irrespective of CD4 count) was started in 2016, and that treatment initiation time had been shortened as a result of the training of 105 nurses to initiate treatment in the 80 facilities they currently support (Right to Care, 2017). Similarly, the TB/HIV Care Association (2016) reported that during a twelve-month period in 2015 it had tested 80,558 prisoners, amongst whom 4,859 (6%) were HIV-positive, and that it had initiated ART for 1,217 (or 50%) of the 2,361 prisoners who were subsequently eligible for treatment. The report did not explain why treatment coverage was not higher, however.

Finally, no data were found on uptake of HIV services for **migrants**, including **undocumented foreigners**.

How, for all groups included in the assessment, human rights barriers affect access to HIV services is discussed in the following sections, beginning with an overview of the general country context for work that addresses human rights concerns, including the large range of laws, policies and plans that are meant to support such efforts.

4.3. Overview of the law and policy context for address human rights barriers

Overall, South Africa has a very supportive law, policy and strategy framework for most of the key and vulnerable populations included in this assessment (sex workers and PWID are the main exceptions) although, as noted below, the realisation of the human rights commitments these frameworks set out remains inconsistent and highly problematic in some instances. Institutions exist to assist with the realisation of human rights, both in the context of HIV and more broadly; however, their effectiveness in doing so, including issues of accessibility and responsiveness, has certain limitations which are largely related to gaps in technical and operational capacities.

4.3.1. Legal framework for HIV-related human rights

The overarching framework for HIV-related human rights concerns is the *Constitution of the Republic of South Africa* (1996) which promotes the fundamental values of dignity, freedom, and equality for all. It outlaws unfair discrimination on a number of grounds, including gender and sexual orientation. Under Section 27, in addition to other items, it stipulates that all citizens have a right to access health care services, including for reproductive health.

In addition to the *Constitution*, the country's commitment to human rights is also evident in the number of international instruments that have been ratified and subsequently domesticated in national laws and policies. These include the African Charter on Human and Peoples' Rights; the African Charter on the Rights and Welfare of the Child; the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa; the Convention on the Rights of the Child; the Convention on the Rights of People with Disabilities; the Convention on the Elimination of All Forms of Discrimination Against Women; the International Covenant on Social, Economic and Cultural Rights; and the International Covenant on Civil and Political Rights (AIDS Rights Alliance for Southern Africa [ARASA], 2016).

South Africa has a number of progressive laws which provide a legally enabling environment in relation to HIV, including laws which promote human rights, non-discrimination, access to justice, and gender equality. The most important of these are summarised below:

- The *Promotion of Equality and Prevention of Unfair Discrimination Act, 2000* (PE-PUDA) elaborates on the constitutional guarantee of equality, with a special focus on equality on the grounds of race, gender and disability. Although the law does not specifically mention HIV, the courts have extended protection to PLHIV under its provisions.
- The Legal Aid South Africa Act, 2014, sets out the government's obligation to provide legal aid and advice, including free legal representation to those who cannot afford it, and to educate and inform the public about their rights and obligations under the Constitution. HIV-related legal claims are included within the scope of this law for PLHIV and others who qualify for free legal assistance.
- Laws addressing HIV-related discrimination in the workplace include the *Labour Relations Act*, 1995, which protects all employees from discrimination and prohibits dismissal on the grounds of HIV status; and the *Employment Equity Act*, 1998, which also prohibits unfair discrimination in any employment policy or practice on various grounds, including HIV status. The law also prohibits certain pre-employment HIV screening. In addition, the *Occupational Health and Safety Act*, 1993 includes provisions on occupational exposure to HIV and gives employees the right to seek compensation. In this regard, the *Compensation for Occupational Injuries and Diseases Act*, 1993 has been amended to include provisions regarding HIV.
- The *Prevention and Combating of Hate Crimes and Hate Speech Bill* is expected to be enacted in 2018. The Act aims to give effect to the South Africa's obligations in terms of the *Constitution* and international human rights instruments concerning various forms of discrimination and intolerance, including on the basis of sexual orientation.

South Africa has also made progress in passing laws addressing gender, including gender identity, sexual and reproductive health and rights (SRHR), and SGBV. Examples include the following:

- The *Domestic Violence Act*, 1998, which recognises a broad range of relationships, including same sex relationships, and protects individuals from physical, sexual, psychological and economic abuse, including marital rape, in these relationships.
- The *Sexual Offences Act*, *2007*, which has a gender-neutral definition of sexual violence and equalises the age of consent for both hetero- and homosexual sex to 16 years. It also makes provision for access to services for survivors of SGBV, including for post-exposure prophylaxis (PEP).
- The *Children's Act, 2010*, which includes protection for a child's right to non-discrimination as well as the rights to provide independent consent to HIV testing from 12 years of age, and the right to confidentiality regarding his or her HIV status (provided they have the maturity to understand the implications of their decisions). Children above the age of 12 years also have a right to access contraception and abortion without the requirement of parental consent.

- The Civil Union Act, 2006, which allows same-sex couples the right to form legally registered unions, including marriage, and also provides for the right of same-sex couples to adopt children.
- The *Alteration of Sex Description Act*,2003, which stipulates that people can change the gender markers on their identity documents.

With regard to relevant regulations and sector-specific policy frameworks, public sector workplaces, including health facilities, are covered under the *Public Service Regulations*, *2001*, whose provisions addressing working conditions, for example, and, as a result of amendments made in 2004, also protect the rights of employees with HIV. Linked to these regulations, the *HIV*, *AIDS and TB Management Policy* (2012) provides a normative framework that supports the effective operationalisation of sectoral HIV strategies and plans. Based on this, different public sectors have enacted an additional range of policy-related protections in relation to HIV, including the Departments of Health, Education, Transport, Correctional Services, and Defence, amongst others.

It is important to note that, with regard to inmates, in 2013, the DCS approved a *Sexual Abuse Policy* to address sexual abuse of inmates in its facilities. The policy was viewed as a major achievement in the fight for the rights of prisoners, as it provided DCS officials with the mandate to intervene by preventing, detecting, responding to and documenting cases of sexual abuse. The policy includes instructions that both condoms and PEP should be available to prisoners. However, as described in **Section 4.4.7**, below, there are major challenges with the implementation of this policy, limiting the potential role it can play to improve access and uptake of HIV services in prison settings in the country.

In 2017, the Department of Health launched the *National Adolescent and Youth Health Policy*, which provides a framework for addressing the holistic health needs of young people, using a progressive, rights-based approach. HIV and TB are addressed under Objective 2: *Provide comprehensive, integrated sexual and reproductive health & rights services integrated with HIV & AIDS & TB*. The policy also recognises that health services should be inclusive and responsive to the needs of young people in all of their diversity.

The legal and regulatory framework for work to address many human rights concerns in the context of HIV is, for the most part, both comprehensive and progressive in South Africa. The extent to which PLHIV and other key and vulnerable populations can realise these rights and benefit from their protections is a point of debate, however, and is discussed under **Section 4.5.5**, below. This legal and regulatory framework is complemented and enhanced by a number of HIV-specific strategies and plans which are described in the next section.

4.3.2. National strategies and plans

South Africa has developed a number of linked, multi-sectoral plans that are specific to HIV and that, for the most part, address the need to remove human rights barriers to HIV services. The most important of these is the *National Strategic Plan for HIV*, *TB and STIs 2017-2022 (NSP)* (SANAC, 2017). The human-rights-based approach is central to this framework and is clearly expressed in Goal 5: *Ground the response to HIV*, *TB and STIs in human rights principles*. The goal has three objectives:

1. Reduce stigma and discrimination among people living with HIV or TB by half by 2022;

- 2. Facilitate access to justice and redress for people living with and vulnerable to HIV and TB; and,
- 3. Promote an environment that enables and protects human and legal rights and prevents stigma and discrimination.

There are a number of sub-objectives that describe specific actions to be taken to achieve the objective. These include:

- Revitalise community-based support groups to deal with internalised stigma;
- Reduce stigma through community education;
- Improve legal literacy about human rights and laws relevant to HIV and TB;
- Implement a Human Rights Accountability Scorecard;
- Monitor implementation of laws, regulations and policies relating to HIV and TB, and identify areas for reform;
- Sensitise law makers and law enforcement agents; and,
- Train health care providers on human rights and medical ethics related to HIV.

This list reflects a clear embodiment of the comprehensive, UNAIDS and Global Fund-defined best-practice approach to addressing human rights concerns in the context of HIV (see **Section 3.1**, above). Human-rights-related components are also included under Goal 3: *Reach all key and vulnerable populations with customised and targeted interventions*. These include:

- Support key and vulnerable population social capital by encouraging community networks that include advocacy agendas for equal health and human rights;
- Further train and sensitise healthcare professionals in the identification and delivery of appropriate services for key and vulnerable populations; and,
- Integrate rights-based components in all health and social programmes to holistically serve key and vulnerable population clients and patients.

In addition, the structural drivers of HIV-related vulnerability are acknowledged in Goal 4: Address the social and structural Drivers of HIV, TB and STIs and link these efforts to the National Development Plan.

The extent to which this comprehensive approached is being implemented country-wide is discussed under **Section 4.5**, below, and, indeed, there are successes as well as on-going gaps and challenges.

There are other HIV-related and population-specific plans that are meant to complement and reinforce the human rights components within the national HIV response. These include South African National Sex Worker HIV Plan (2016-2019) for which Goal 3 is, Reduce human right violations amongst sex workers (SANAC, 2016a). The goal is linked to Objective 6 which stipulates, ensure the development and implementation of effective mechanisms to deal with human rights abuses and violence from non-commercial sex partners, clients, police and health care providers, through sensitisation of police and prosecuting authorities and legal and paralegal support. One of the plan's targets is, reduce instances of violence against sex workers by 50%.

The country has also put in place the *South Africa National LGBTI HIV Plan 2017-2022* (SANAC, 2016b). The strategic approach to human rights issues is similar to the national sex worker plan in that Objective 4--Human Rights states, to develop and implement effective mechanisms to deal with human rights abuses and violence from the public, police and health care providers; sensitisation of police and prosecuting authorities; and legal literacy and paralegal support to reduce violence against *LGBTI*. Through peer and community led approaches, the plan aims to reduce instances of stigma, discrimination and violence in the context of HIV, and to promote and protect human rights across all lesbian, gay, bisexual, transgender and intersex (LGBTI) constituencies.

No HIV plans have been developed regarding PWID. The *National Drug Master Plan (NDMP)* 2013-2017 acknowledges the link between drug and alcohol use and HIV but does not mention the human rights of drug users, or address issues of stigma and discrimination (Department of Social Development [DSD], 2013). The NDMP notes that the concept of harm reduction was debated during the development of the plan, with some Central Drug Authority (CDA) members being of the view that the term "appears to condone drug use" (KII with CDA, November 2017).

SANAC has indicated that it intends to initiate the process of developing a national HIV plan for prisoners in 2018 (KII with SANAC).

There are other sectoral strategies that address HIV in South Africa but not all contain explicit components related to human rights concerns. For this assessment, the *National Adolescent Sexual and Reproductive Health and Rights Framework Strategy 2014—2019* is the more significant (DSD, 2014). The document acknowledges the following barriers to the health and rights of adolescents: lack of sexuality education; non-involvement of males; reluctance to acknowledge adolescents' sexual curiosity; homophobia; and, gender-based violence. In response, the strategy proposes increasing co-ordination, collaboration, information and knowledge-sharing on adolescent SRHR; developing innovative approaches; strengthening service delivery and support on various health concerns, including HIV; creating effective community support networks for adolescents; and, formulating evidence-based revisions to laws, policies, strategies and guidelines on adolescent SRHR. Again, the extent to which the strategy is implemented, is a subject of debate.

4.3.3. State entities for the protection and promotion of human rights and gender equality

South Africa has a number of government entities, including special courts, with mandates to deal with specific types or categories of human rights issues. These include the South African

Human Rights Commission (SAHRC); the Commission for Gender Equality; Judicial Inspectorate of Prisons; and, various Parliamentary Committees that monitor the implementation of laws and policies. Specialised courts have also been set up with the aim of improving citizens' access to justice without the need for formal or private legal representation. These include Sexual Offences Courts, that are operated by the Department of Justice in 36 locations country-wide, and Equality Courts. These latter bodies have been operational since late 2003. Their purpose is to adjudicate matters specifically relating to infringements of the right to equality, unfair discrimination, and hate speech. The role of the Equality Courts in addressing human rights barriers to accessing HIV and TB services, as well as their effectiveness, is discussed in **Section 4.5.6**, below.

In general, then, the law, policy and strategy context is mostly favourable in the way that it acknowledges human rights concerns in the context of HIV, specifically for the key and vulnerable populations included in the assessment; and in the way that it provides for a number of ways that such concerns can be addressed through a variety of mechanisms. The extent to which PLHIV and individuals from other key or vulnerable populations benefit from this context, however, and that it actually improves their uptake and retention in HIV services, remain debatable. What constitutes these on-going barriers and gaps is described in the next section.

4.4. Human rights barriers to HIV services

4.4.1. Overview

The findings in this section consolidate information derived from the desk review and the fieldwork. They show that, overall, HIV-related stigma and discrimination, in a variety forms and with different impacts, against PLHIV and other key and vulnerable populations, remain a dominant barrier for access and uptake of HIV services. While instances of discrimination and poor service quality for PLHIV are declining in South Africa, more substantial challenges remain for key populations outside of the limited number of key-population-friendly services that are currently available. The criminalisation of sex work drives human rights violations which are associated with some of the highest rates of HIV globally amongst this group. Laws against drug use limit the development of harm reduction interventions for PWID and also drive discrimination, violence and abuse against them.

Major challenges of structures and systems within the country's prison system place both sentenced inmates and those being held in remand at high risk of HIV, TB and a number of other serious health conditions. Even with the support of a number of partners, the DCS still struggles to be able to provide comprehensive HIV services to those under its care. Finally, highly problematic attitudes and practices, particularly the exceedingly high rate of SGBV, continue to place adolescent girls and young women at high risk of HIV infection and also limits their ability to use HIV and other services when they need them. All of these items are described in more detail in the sections that follow.

4.4.2. Stigma, discrimination and violence

The findings in this section are discussed first for PLHIV and then for the other key and vulnerable populations included in the assessment (issues for adolescent girls and young women are discussed in **Section 4.4.8**, below). To arrive at these findings, the assessment used both quantitative and qualitative results. On the quantitative side, for PLHIV, the PLHIV Stigma Index Survey on HIV- and TB-related stigma in South Africa, conducted in 2014, provides the

most recent data (SANAC, 2015). Over 10,000 PLHIV participated; however, only 3% of participants self-identified as being a member of a key or vulnerable population, which included MSM, sex workers, transgender, prisoners or foreign migrants.

Overall, the study indicated that HIV-related stigma and discrimination continued to prevail across South Africa, with just over one-third of respondents (36%) having experienced some form of stigma in either their personal and social environments. This included being gossiped about (the most frequently cited from of external stigma), and experiencing verbal and physical harassment or assault. Regarding internalised stigma, 43% of respondents reported experiencing it, usually in the form of shame, guilt, self-blame or low self-esteem. Levels of both external and self-stigma were highest for younger participants (15-24 years); amongst women living with HIV; and for participants in the three provinces with the highest rates of HIV prevalence, which were Free State, Mpumalanga and KZN. Very few PLHIV reported experiencing HIV-related discrimination in housing or employment (≤10%). Of those that did experience workplace related issues, approximately 40% felt it was directly related to their HIV status.

Finally, almost no respondents (≤5%) indicated that they had been denied health services. However, there is a distinction between being denied services and being provided with poor quality or stigmatising services that is explored more fully in **Section 4.4.3**, below. The report concluded that, whereas great strides had been made with regards to combating stigma and discrimination against PLHIV, more work needed to be done to eliminate this, to avoid complacency, and to keep anti-stigma work on the national agenda. The report raised concern about the levels of self-stigma, and suggested that this was probably a consequence of the lack of adequate psychosocial support available to PLHIV.

The findings from the fieldwork largely supported this analysis. In encounters with PLHIV networks and PLHIV representatives in the different geographic locations where the fieldwork took place, similar accounts of instances of external and self-stigma were shared (FGDs with PLHIV networks and Treatment Action Campaign (TAC), November 2017). However, there was some reflection on why this was still occurring, given all of the effort in the country to raise awareness regarding HIV as well as the large numbers of PLHIV that are present in almost every community and family country-wide. These key informants suggested that, like other deeply held cultural practices and beliefs, individual and community-level perceptions and understandings about what HIV signified for an individual--that they were promiscuous or that, as men, they were weak, for example--continued to have a strong hold and to drive the 'epidemic' of self-stigma and shame amongst many PLHIV themselves. There were a number of accounts of the consequences of self-stigma, including individuals either not starting ART or not continuing ART because they did not want to be seen at health centres or did not want family members or friends to find them with medication. Treatment interruptions were also said to occur when an individual started ART at a health facility far from their own community but who could not subsequently afford transport costs and still would not go to the facility in their own community (KIIs with TAC and Positive Convention Network, November 2017).

Some informants suggested that poverty was also a driver of HIV-related stigma, in the sense that competition for scarce resources affected human behaviour such that people would use any means, including malicious gossip about someone's HIV status, to prevent someone else from 'getting ahead of them.' Poverty was also said to be a factor in negative experiences in the workplace where HIV-related discrimination was used as a way to move an individual out of a position so that someone else could take it. These informants also spoke about employers' intolerance to workers' needs, including for HIV, and how some individuals made it clear to

their employees that there were others waiting to take their jobs if they needed too much time for medical appointments or were ill too often (KIIs with TAC, Positive Convention Network, National Association of People Living with HIV and AIDS [NAPWA], November 2017). Given limited opportunities for employment for a great many South Africans, including those living with HIV, it was not surprising to hear accounts of some PLHIV going to great lengths to hide their HIV status and to even deny their health needs so as not to risk losing work in either the formal or informal employment sectors.

Several key informants suggested that traditional cultural values posed a significant challenge in that they drove stigma, discrimination, violence and hate crimes; this was particularly salient in rural areas (KIIs with DOH; Masimanyane, Social, Health and Empowerment Feminist Collective of Transgender Women of Africa [SHE]; Centers for Disease Control and Prevention [CDC]; NACOSA; Department of Basic Education [DBE], November December 2017). Traditional cultural values were said to be highly patriarchal and hetero-normative, ascribing lower status to women, and enforcing narrow conceptions of gender and sexuality. Practices such as virginity testing, forced marriages and forced traditional circumcision were raised as being problematic. Leaders were viewed as playing a key role in influencing norms and practices. These findings were supported by the report from the Hate Crimes Working Group, which monitored hate crimes in South Africa from 2013-2017, and found that rhetoric plays a role in condemning those who are perceived as not conforming to community expectations, which eventually breeds hatred and legitimises hate crimes (Mitchell and Nel, 2017).

Findings from the desk review and fieldwork presented a bleaker picture for key populations. For example, numerous studies have drawn attention to high levels of stigma, discrimination and violence against sex workers, as well as against gay men, transgender and other LGBTI individuals. The most recent data on these issues are summarised below:

- **Sex Workers:** There is a long history of discrimination against sex workers by clients, the police, HCWs and the justice system (Fick, 2006; Scorgie et al., 2011; Richter and Chakuvinga, 2012). For example, in 2012, 50.9% of sex workers in Johannesburg, 47.3% in Cape Town and 14.1% in Durban reported having been physically assaulted at least once in the preceding 12 months (UCSF et al., 2013). More recent data suggest that that rights-based interventions have slowly begun to reduce the levels of discrimination and stigma which sex workers experience (Scheibe et al., 2016a; Rangasami et al., 2016).
- MSM: A number of studies in the last decade have documented instances of violence (physical and psychological, including blackmail), harassment by police, denial of health services, inadequate health services, and internalised stigma (Anova, 2013; DOH and SANAC, 2015). More recent work, involving a sample of 2 100 participants, for which more than 60% were gay or bisexual men, found that 55% of these individuals feared discrimination on the basis of their sexual orientation and that 44% had experience some form of discrimination in the past 24 months (OUT Right LGBT Well-Being [OUT], 2016). The most commonly reported types of discrimination were verbal insults, being threatened with physical violence, or being chased or followed.
- Other LGBTI: Disaggregated data from this same study showed that 24% of transgender participants had been threatened with physical violence and a further 13% had been assaulted. As noted above, SANAC (2016) recorded that 31-45% of WSW have

reported experiences of forced sex and rape. The horrendous phenomenon of sexual violence, often gang rape, against lesbians and transgender men (so-called 'corrective rape') continues to be widespread in South Africa (Koraan, 2015). The murder of women targeted for being lesbian has been called, "the silent genocide of South Africa's townships." 3

These findings on external stigma and discrimination against key populations were to a great extent confirmed by the fieldwork, although in some instances it was difficult to move from compelling individual accounts to a perspective of the current, overall, frequency or magnitude at a provincial or country level. Key informants also explained how these experiences drive levels of self-stigma and how this 'causal' chain both increases risk of HIV infection and negatively affects health seeking behaviour to mitigate this risk. To illustrate this, one key informant noted the following:

"Sex workers accept violence and rape, but it has long-term effects on their lives — they don't seek help when it happens... you find they have defaulted [on ART] and when you go back you discover they were raped when young or while working and they have low self-esteem." (KII with SWEAT Eastern Cape, December 2017)

Other informants spoke of similar issues in their work with key population programme users. They described how some clients lived with a lifelong history of rejection, abuse or violence within families, schools and communities (KIIs with OUT, SHE, Triangle Project and SWEAT, November-December 2017). The long-term impact of these repeated experiences was a valid belief that the external environment was too hostile to express oneself freely and live freely, giving rise to the expectation that whatever one does, one will be mistreated. Another consequence is a strong current of internalised, negative self-beliefs, such as low self-esteem and low self-worth. These strongly affect health seeking behaviour, including participation in HIV programmes, and also have links with different forms of mental illness, such as depression, anxiety, and substance abuse. 4

While, as the findings show, different forms of external and self-stigma, as well a more troubling trend of verbal and physical violence and abuse, including sexual violence, continue to have complex, deterring effects on access to HIV services, other barriers arise in terms of how such services are organised and provided. These are discussed in the next section.

4.4.3. Stigma and discrimination in health services

Stigma and discrimination in health services was explored at length by the assessment, both through the desk review and amongst the assessment participants themselves. Collectively, the findings demonstrated that substantial challenges are present in how HIV services are structured and provided, both through the public health system and through the wide range of non-governmental entities that participate in the national HIV response in South Africa. Some of these challenges are broadly structural and affect all health systems users. Others are

³ See: http://iranti-org.co.za/content/Africa_by_country/South_Africa/2016-LGBTI-genocide/2016-South-Africa-lgbti-genocide.html

⁴ These relationships have been modelled for MSM, for example, in a recent study from Lesotho. See Wendi D et al. 2016. Depressive symptoms and substance use as mediators of stigma affecting men who have sex with men in Lesotho: a structural equation modelling approach. *Annals of Epidemiology* 26(8): 551-556.

very specific to PLHIV and the other key and vulnerable populations included in the assessment.

With regard to structural challenges, while instances of stigma and discrimination against key and vulnerable populations in provision of HIV services were reported by many assessment participants, including key informants and focus group participants, almost all were generally mindful of the larger context of severe challenges in the country's public health system overall (KII and FGDs with PLHIV and key population representatives, OUT, UNFPA, Amnesty International, November-December, 2017). It was acknowledged, for example, that HCWs have high patient loads, and work in congested and understaffed facilities. Several participants further remarked that HCWs experience high levels of stress, trauma and burnout, and that there are inadequate measures in place to provide them with psychological support.

Nevertheless, it was still observed that "rude, disrespectful, harsh, cruel, uncaring and abusive" attitudes and behaviours on the part of these individuals was a widespread problem directed towards all users of the public health system. These observations were further bolstered by recent research (Bogart et al., 2013; Haskins et al, 2014; Honikman et al., 2015). Media reporting on nurses and their situation has generally been negative in the country in the way that it has portrayed nurses as, "overworked, uncaring, lazy, ruthless, incompetent and suffering from burnout (Ooshtuizen, 2012)." A recent example of this was a headline that read, "Rude nurses put young women off HIV treatment (Seid, 2017)." Faced with such issues, the South African Nursing Council has been accused of being "largely dysfunctional" as a regulatory body and providing "sub-optimal leadership in policy development and implementation (Rispel and Bruce, 2015)."

For assessment participants, while they were generally cognisant of these structural and system-wide issues, they further argued that people who deviate from the dominant socio-cultural norms are more prone to being the targets of these negative attitudes and behaviours than members of the general population (KIIs with OUT and ANOVA, December 2017). Against this background, and in line with the research findings, participants described how public health services are both ignorant and insensitive regarding diversity in terms of sexual orientation and gender identity (see, for example, Rispel et al., 2011; and Scheibe et al., 2017a). This is also true for public sector HIV services where, for example, the wording of HIV guidelines and the content of health education materials (including pictures and diagrams) reflect only heterosexual realities such that non-heterosexual service users, particularly MSM, feel "invisible" when they attempt to use these services (KII with ANOVA, December 2017).

Key informants also noted that HCW lack adequate knowledge about key populations generally and about their health needs more specifically. It was the view of many assessment participants that basic training for HCW was outdated and did not equip them with an understanding of issues related to gender and sexual diversity (KIIs with ANOVA and UNFPA, December 2017). For example, it was noted that history-taking, screening and diagnostic processes are based on the assumption that sex is heterosexual and vaginal. Thus, for example, there is ignorance about oral or anal sexual health challenges. Assessment participants shared several examples as to how this lack of knowledge and awareness manifests itself, including one particularly troubling example involving a lack of adequate sexual and reproductive health knowledge on the parts of both the HCW and the patient. One assessment participant described how a young MSM from the Eastern Cape with a bleeding anal STI, and not under-

standing what was wrong with him, told the nurse that he was menstruating. The nurse apparently scoffed, told him that was impossible, did not examine him, and sent him away (KII with ANOVA, December 2017).

As another category of issues, it was widely reported that health facility staff express stigmatising attitudes towards key populations. Although these were said to occur from all cadres of staff, a majority of assessment participants singled out non-clinical staff, especially security guards, but also clerks and cleaners, as the most problematic, one reason being that they are rarely if ever involved in training and sensitisation activities that are provided for their clinical colleagues. Research findings bolster these observations, particularly for MSM and for foreign migrants (Rispel et al., 2011; Vearey, 2014). As a further example, peer educators working with PWID described how their clients are frequently barred from facilities by security guards, either because of their appearance or because it has become known that they are a PWID (KII with OUT, November 2017).

In addition to these concerns regarding non-clinical staff, the problem of stigmatising and discriminatory behaviour on the part of clinical staff was raised by all key informants working with key and vulnerable population groups (MSM, WSW, transgender people, sex workers, PWID and migrants). These challenges appeared to be most severe for transgender people and PWID (KII with Right to Care, ANOVA and OUT, November-December, 2017). Nevertheless, gay men and other MSM still experienced a range of negative attitudes towards them on the basis of their sexual orientation, including the posing of invasive, prurient, non-relevant questions about their private and sexual lives. In addition, some individuals were sometimes subjected to religious judgements and sermonising (see also Maleke et al., 2017).

Transgender people were often treated as oddities or freaks (KIIs with SHE, ANOVA, and Right to Care, November-December 2017). One form of this that was described by several key informants involved nurses who, once they found out that a transgender woman was biologically male, would express shock and then call other colleagues to view the patient and who would then ridicule and speak loudly about her so that others would overhear. PWID were said to experience double stigma in health facilities (KII with OUT, December 2017). Firstly, it was because of the high level of homelessness among PWID in response to which nurses looked down upon them as "dirty and smelly." It was said that, subsequently, nurses made a show of moving away, or opening windows, or waving their hands in front of their noses. Secondly, once facility staff discovered that the patient was a PWID, they would "recoil in horror", and say things like: "You are doing this to yourself," "Come back when you are clean," and "Why should we waste taxpayers' money to help you?" (KII with OUT, December 2017). PWID peer educators reported that, as a result of such attitudes and practices, PWID were sometimes denied services altogether, made to wait longer than other patients, or were denied medication, including ARVs.

As an additional category of concerns, it was expressed by many assessment participants that HCW did not uphold professional ethics. Breaches of confidentiality and gossiping were common (KIIs with Soweto HIV/AIDS Counsellors Association [SOHACA] and OUT, November 2017). Thus, individuals from key populations feared that nurses would disclose their personal information, including their sexual orientation or their HIV status, outside of the clinic setting and that rumours would then spread throughout the community. Fear of being outed, as an MSM as well as an MSM living with HIV, was related not just to a fear of being socially ostracised, but also of having an increased risk for physical violence.

Assessment participants, particularly those from PLHIV networks, suggested that, while in some cases, breaches in confidentiality were deliberate, often these breaches arose as unintended consequences of facility structures, procedures and processes. For example, in congested and inadequately ventilated facilities, in order to reduce the spread of TB, staff might leave the consulting room door open, with the result that the people in the waiting areas could overhear discussions happening inside. Other examples included the use of specific colour files or stickers for PLHIV, or specific rooms, queues or clinic days (KIIs with PLHIV networks and TAC, November-December 2017). One key informant described how, in one ante-natal clinic in Mpumalanga, patients reported that, due to lack of space, phlebotomy was done in the clinic waiting area and that it was well-known by patients that if one vial of blood was taken, the patient was HIV-negative, while two vials meant he or she was HIV-positive (KII with Amnesty International, Mpumalanga, 2017).

The combined impact, then, of these different categories of health-care-related stigmatising and discriminatory beliefs, attitudes and practices was, according to assessment participants, a strong aversion to and avoidance of public health facilities, including delays in seeking needed services or, at times, an outright refusal to attend, with a negative outcome across the entire HIV continuum of care. Individuals who could afford to would either attend private doctors, or, more commonly, attempt to manage symptoms through self-medication.

A number of compelling accounts of this negative trend were given by assessment participants. For example, peer educators working with sex workers from Qholaqhwe LAC, in rural eastern Free State, described how, when providing HIV testing and supporting those who test HIV-positive, they "refer them to clinics to start treatment and they refuse, even when they have peer educators to go with them (KII with peer educators, Qholaqhwe LAC, November, 2017)." Similarly, individuals working for a SWEAT-supported peer education and navigation project in Eastern Cape spoke about the disastrous consequences of a gap in funding (KII with SWEAT, November 2017). During that 15-month period, the peer leader reported, "There was a lot of defaulting, and we found many passed away... they didn't want to go to the facilities without a peer, or maybe the health care worker wasn't as accepting when we weren't there." As another example from Emalahleni district, staff from the TB/HIV Care Association described how, during the gap between two successive CDC grants, when the implementing partner in that district changed, "90% of sex workers stopped going for treatment." (KII with TB/HIV Care Association, November 2017)

There were more examples for other key population groups, such as this comment from a peer outreach worker supporting PWID: "PWID only go to hospital when they are at death's door, or are found unconscious." With regard to MSM, Maleke et al. (2017) found that some of the MSM participants preferred consulting traditional healers for HIV-related ailments for two reasons: firstly, because some traditional healers are LGBTI themselves; and, secondly, because of the perception that traditional healers were more likely to uphold confidentiality.

As a final category of concerns, and with more general regard to HIV programmes for key populations, assessment participants noted several flaws in their conceptualisation and their implementation which led to inadequate outcomes, including the direct or indirect perpetuation of stigma. Representatives from community-based, key-population-led organisations raised concerns about programmes which were being implemented by large HIV and health NGOs as an add-on to their existing programmes, and that, while these organisations may be well-resourced, and well capacitated for programme management, they lacked experience in and knowledge about key populations. Further, key population representatives were said to

be inadequately consulted or represented within these programmes. The consequence was that there were barriers to these programmes' gaining the trust and participation of their intended beneficiaries. They were also said to be narrowly focussed on HIV outcomes, with aggressive targets for HTS and referral for ART, for example, and did not address broader sexual health or psychosocial needs, or human rights violations, which were themselves drivers of HIV risk and deterrents to access to services.

It was also observed that the DOH's High Transmission Area (HTA) programme, which is supposed to reach key populations with HIV prevention interventions, consists mainly of community health workers or 'peer' educators who are not themselves members of key populations (it was noted that they are mostly older women), who have limited understanding of key populations; who may even themselves hold stigmatising attitudes; and who are thus also limited in their ability to access key populations networks (KII with DOH representatives, November 2017). Finally, some assessment participants gave examples of inadvertent stigmatisation or potential exposure of key populations, including the setting up gazebos to test MSM at shopping malls, or highly visible, branded mobile clinics providing outreach services to criminalised populations.

4.4.4. Punitive laws, policies and practices

South Africa's Global AIDS Response Progress Reporting (GARPR) submission for 2015, the most recent narrative report that the country has made, noted that a comprehensive and systematic audit of HIV-related human rights violations and the laws, policies and programmatic interventions which contribute to these violations, had not yet been undertaken (SANAC, 2016). It also noted that SANAC, nor any other government body, was not adequately invested in the monitoring of these trends. However, in spite of this, the report concluded that:

"...despite the absence of a formal and co-ordinated audit of all laws, policies, programmes and practices, it appears that there is a good understanding of where and how human rights violations are taking place and which populations are most affected."

The baseline assessment findings were similar and highlighted that, in general, the laws and policies in South Africa are very supportive of access and uptake of HIV and TB services for PLHIV and other key or vulnerable populations (with a few notable exceptions discussed below). Moreover, laws relating to adolescent SRHR have been hailed as 'best practices' on the African continent (UNFPA, 2017). Where challenges remain is with regard to implementation and enforcement of these provisions; general knowledge about legal and human rights as they relate to accessing these services; and, the effective functioning of mechanisms giving rise to justice and redress in situations where people have been poorly treated or denied services. Problematic police practices - against sex workers and PWID in particular - which violate the country's citizens' right to access health services, including HIV services, were found to be a widespread trend. Finally, the country's prison system remains in the grip of complex structural and system-wide challenges limiting what DCS and it supporting partners can achieve with respect to the provision of HIV and TB programmes.

4.4.4.1. Challenges with laws and policies

South Africa's rights-affirming Constitution and relatively progressive jurisprudence were widely acknowledged by assessment participants as enablers of their efforts to address human

rights barriers. However, laws pertaining to sex work and laws dealing with drug use were identified as impediments (challenges for law and policy regarding SRHR for adolescents, particularly for adolescent girls, are discussed in **Section 4.4.8**, below).

Laws and policies relating to sex work

The continued criminalisation of sex work was raised repeatedly by assessment participants from a broad range of constituencies and entities as a main human rights barrier to effective HIV programming for this group which bears the highest burden of HIV in the country. For South Africa, the following laws uphold the criminal nature of sex work:

- Provisions of the Sexual Offences Act 23, 1957 that continue to be applied and that state that any individual who has "unlawful carnal intercourse or an act of indecency with any other person for reward commits an offence." It makes illegal prostitution, brothel keeping, solicitation, indecent exposure, and knowingly living from the proceeds of sex work.
- Provisions of the Sexual Offences and Related Matters Amendment Act, 2007 that criminalise clients who engage the services of sex worker.

These legal provisions, which have a hugely disproportionate impact on sex workers and not clients, fuel a wide range of violent and abusive practices against them, including denial of HIV services and interruptions of HIV treatment. Sex workers are most frequently arrested and harassed under municipal by-laws. For example, it has been documented that sex workers are sometimes fined under the *By-law relating to Streets, Public Places and the Prevention of Noise Nuisance GN 6469 28/09/2007, Section2 (3) (j)*. In many cases of arrest, the sex worker has not actually committed the offence in question, and even when she is guilty of that offence, the correct procedure for addressing such infractions is not usually followed. Rather, it is simply used to harass these women and to extort money (Women's Legal Centre, 2012).

A long delayed but recently released report by the South African Law Reform Commission (SALRC) on Adult Prostitution recommended the continued criminalisation of sex work, an outcome that many assessment participants insisted was out of step with South Africa's human rights framework and the recommendations of global bodies such as UNAIDS, WHO, Amnesty International and Human Rights Watch (SALRC, 2017), which have called for full decriminalisation. Key informants noted how criminalisation fuelled stigma, discrimination and violence against sex workers, how it created a culture of impunity, and how it deterred sex workers from reporting crimes against them.

As an additional influence on the HIV-related programme environment for sex workers, although not a South African policy, the United States Government's (USG) Anti-Prostitution Loyalty Oath (APLO) has implications for USG-supported HIV programmes in the country. According to the *Leadership Against HIV/ AIDS, Tuberculosis, and Malaria Act of 2003*, all non-US NGOs that receive USG grants (for example, from PEPFAR, United States Agency for International Development (USAID), or Centers for Disease Control and Prevention (CDC)) are required to sign an agreement that commits them to the following:

No funds made available to carry out this chapter, or any amendment made by this chapter, may be used to provide assistance to any group or organisation that does not have a policy explicitly opposing prostitution and sex trafficking⁵

The APLO was viewed as being a barrier to the implementation of comprehensive, rights-based HIV programmes for sex workers in line with global guidelines (KIIs with CDC, Sonke Gender Justice, and SWEAT, November-December, 2017). This barrier is significant given the substantial support available through PEPFAR for key population programmes (there are further details about the magnitude of this support in **Section 6**, below).

Laws and policies regarding drug use

Laws relating to drug use were seen by assessment participants as imposing barriers on PWID to access and remain in HIV services, and imposing limits on what could be provided in terms of HIV prevention and other harm reduction interventions (KII with OUT, November 2017). According to the *Drugs and Drug Trafficking Act*, 1992, it is illegal to use, carry and deal in narcotic substances. Within a framework of criminalisation, most policies do not consider alternatives to the traditional abstention model. Law and policy makers were reported to be resistant to adopting a harm reduction approach (KII with CDA, December, 2017).

While drug laws do make provision for diversion to rehabilitation for people charged with drug possession, it was perceived that magistrates default to sentencing drug users to prison terms (KII with OUT, November, 2017). Such sentences compound the HIV risks associated with PWID by adding those HIV risks associated with incarceration. Furthermore, criminal records increase the stigmatisation and marginalisation of PWID once they are released. In addition, it was noted by assessment participants that, despite the fact that the NSP recommends needle and syringe exchange interventions and OST, in line with WHO recommendations, amongst others, the law contradicts these, making such interventions either very risky or impossible. Thus, some assessment participants described how there were cases in which peer educators distributing clean injecting equipment had been harassed or obstructed, or even arrested and charged with contravening the law (KII with OUT, November, 2017).

4.4.4.2. Barriers to access to justice

Despite an array of commendable state institutions designed to promote and extend access to justice to all citizens, including the SAHRC, the Sexual Offences Courts, the Equality Courts, Legal Aid South Africa, and Thuthuzela Care Centres, among others, the findings of the baseline assessment were that, from both within and outside of these institutions, there were challenges of either technical or operational (funding) capacity, or both, for many of them to fulfil their mandates. Some participants from civil society were of the view that many South Africans were not aware of these institutions and resources, and the services to which they were entitled.

This finding was supported by some of the institutions themselves where, for example, for a period of time in 2014, Legal Aid South Africa, together with SANAC, were funded to provide legal services to PLHIV and others who experienced HIV-related discrimination (this programme is discussed in more detail in **Section 4.5.2**, below) (KII with SANAC, December 2017). For as long as funding was available, the services were promoted through a variety of

26

⁵ Section 22 U.S.C. § 7631(f)

media channels and this generated strong demand and an increase in reported cases. However, once the media work was no longer funded, the number of reported cases fell markedly. Similarly, the Department of Justice and Constitutional Development (DOJCD) acknowledged that, partly for financial and capacity reasons, it was not doing enough to promote the work and services of the SAHRC and the Equality Courts as places where HIV-related legal issues could be addressed (KII with DOJCD, November 2017).

4.4.4.3. Punitive police practices towards key populations

Police practices were viewed by many assessment participants from key populations as acting as barriers to accessing HIV services and for interfering with HIV treatment adherence, amongst other things. Instances of human rights abuses on the part of the police were highest for sex workers and PWID, according to informants (KIIs with ANOVA, OUT, NACOSA, Right to Care, November-December 2017). However, data and other information continue to show that gay men and other MSM, lesbians and transgender also experience discriminatory police practices.

For examples, representatives from LGBT organisations that participated in the assessment stated that, although gay men and other MSM were not targeted for arrest by the police, when they did experience sexual or physical violence or abuse, they were reluctant to report these crimes (KII with LGBT organisations, November-December, 2017). This reluctance stemmed from an unwillingness to disclose themselves as gay or lesbian in their communities, as well as from an expectation that police would not help them and that they shared the homophobic attitudes of the rest of the community. As one representative from a transgender organisation described, "we become the laughing stock of police when we try to report hate crimes or violence (KII with SHE, November 2017)." While it was stated by many assessment participants that lack of confidence in the police is widespread across South Africa, such distrust is greater amongst key populations. Recent data collected by OUT LGBT Well-Being and its partners show that, of LGBT individuals experiencing sexual or physical violence or abuse, 80% were reluctant to report these criminal acts to the police for fear of further stigma, discrimination or abuse (OUT LGBT Well-Being, 2016).

Sex workers and PWID have harsher experiences due to criminalisation, which gives rise to a constant fear of arrest. These groups also experience widespread harassment, and abuse of power from the police. A range of human rights violations against sex workers have been documented, ranging from routine harassment and intimidation; arrest without probable cause and without following police procedure; being profiled as a 'known sex worker' and arrested while not working; being sprayed with pepper spray (including in the vagina); sprayed with fire hoses or shot with rubber bullets; dropping sex workers far out of town in isolated areas; and of police demanding either bribes or free sex in exchange for not being arrested (Women's Legal Centre, 2012; Aids Fonds, 2016; SWEAT, 2018). In addition, the police practice of using condoms as evidence of sex work, and destroying condoms, has been documented in South Africa, with one study finding that "carrying a condom" was the ground for arrest in 26% of sex worker cases (Aids Fonds, 2016). One assessment participant described how national anti-crime campaigns, such as Operation Fiela, which targeted "drug and prostitution rings," as well as undocumented foreigners, drove sex workers further underground and away from HIV services (KII with Qholaqhwe LAC, November 2017).

Assessment participants working with PWID described how, because of their visibility, these individuals are seen as "easy pickings" for police whom, it was said, have monthly arrest quotas

(KIIs with OUT, SWEAT and Sisonke, November 2017). They also described how PWID felt that police behaved with impunity in harassing them; profiling them; in confiscating or destroying their property (including their ARVs, OST, clean injecting equipment, or their identity documents); and in arresting them without following police procedure. It was said that, for both sex workers and PWID, police would frequently arrest them on Fridays, keep them in the police cells for the weekend, after which they would appear before a magistrate on a Monday and pay a fine. While in custody, both sex workers and PWID were regularly refused access to their medication, including ARVs or OST (KIIs with OUT, SWEAT, Sisonke, November 2017). For PWID who were sentenced after arrest, one key informant described how, for his clients, being re-initiated on ART can take up to three weeks or longer. Police harassment and abuse of PWID and sex workers can also be directed towards peer educators who are part of HIV prevention programmes, some of whom have also been arrested according to assessment participants (KII with SWEAT and OUT, November, 2017).

4.4.4.4. Challenges for people in prisons

Inmates are a key population for both HIV and TB and face a particular set of barriers, due to the fact that they are in an environment in which they have been deprived of their liberty, and are fully reliant on others to support their HIV, TB and other health needs.⁶ However, these restrictions do not extend to limitations on the right to health or health services as stipulated by the country's *Constitution* and related laws and policies governing prisons. While HIV and TB services are provided in prisons by DCS, with support from a number of partners, issues related to stigma and discrimination, abuses of power and the social structures amongst inmates limit how many can access them. Specific issues regarding HIV services are discussed here; those related to TB services are discussed in **Section 5.4.2**, below. However, as the findings make clear, in many instances the issues and challenges are the same.

For example, HIV-related stigma and discrimination towards male inmates (who constitute the majority of incarcerated people) is linked to the taboo around same-sex sexual activity, both consensual and non-consensual, which is known to take place in prison settings, but which is not openly acknowledged (KIIs with SA Partners and Just Detention, November 2017). Furthermore, prisons in South Africa have a complex social structure, in which prison gangs control the day-to-day lives of inmates, including access to authorities, services and other privileges (KIIs with SA Partners and Just Detention, November 2017). DCS members (as wardens or guards are known in South Africa) acknowledge the power and authority of these gangs, and negotiate access to prisoners through gang leaders. Within this context, inmates under-report rape and sexual assault cases, as well as STIs, for fear of future violence (from gang members and other inmates) and reprisals or loss of privileges from members. Reporting a case of sexual violence and gaining access to PEP are also seen as reserved only for those who "lay a charge or point out a perpetrator," and, as a result, inmates are hesitant to do so for fear of experiencing further abuse for laying such a charge (KIIs with SA Partners and Just Detention, November, 2017).

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⁶ It is important to note that no individuals from DCS were interviewed as the period established for data collection did not anticipate the time needed for institutional approvals to occur. An important perspective is therefore not captured in this section. Also, the assessment did not address issues for female or juvenile inmates.

Assessment participants described how sex between male prisoners is a complex phenomenon, in that it is part of South African prison-gang culture and is one of the 'currencies' of prison transactions and is used to obtain favours, privileges or protection (KIIs with SA Partners and Just Detention, November 2017). Despite the adoption of a Sexual Abuse Policy, noted above, in the view of key informants, the plight of prisoners remains largely unchanged. The policy is understandably controversial, as it addresses the taboo subject of sex between inmates around which there is denial and considerable discomfort. Some prison officials do not agree with, and therefore obstruct implementation of, the policy, according to some key informants. Both the provision of condoms by NGOs and the acceptance of those condoms by inmates are considered as 'promoting sodomy' (KII with SA Partners, November 2017). As one key informant stated, "Many inmates don't even know if they were raped or if it was consensual. Officials just say they're gay when rape happens" (KII with Sonke Gender Justice, November 2017). Upon release from DCS, inmates with HIV often do not seek care for their condition and do not disclose their HIV status to others for fear that those around them, including healthcare workers, will suspect that they acquired HIV while in prison and will assume that they are 'gay' (KII with SA Partners, November 2017).

There are other challenges in prison settings for access and uptake of HIV services. Staff shortages, including for HCWs, limit how and when services can be used. Inmates must be accompanied by members to use these services which becomes a practical challenge when facilities are under-staffed. The most serious challenges are for individuals in temporary detention to await trial or to await sentencing. Both judicial processes and public inquiries have drawn attention to the inhumane conditions in which such individuals are held and their lack of access to health services, including those for HIV and TB. While DCS has acknowledged these concerns, progress to address them has been slow for a number of reasons, including the costs and complexities for addressing infrastructural challenges, but also as a result of lack of commitment at senior levels, according to some key informants (KIIs with Sonke Gender Justice, SA Partners and Just Detention, November 2017).

4.4.5. Challenges for adolescent girls and young women to access HIV services

This component of the assessment focussed on barriers to HIV services that affect adolescent girls and young women as well as other gender-related concerns that similarly inhibit access to services for other groups, particularly key populations.

4.4.5.1. Stigma and discrimination in the provision of health services

Both the desk review and the fieldwork highlighted the elevated levels of stigma and discrimination many adolescent girls and young women face when seeking health services, particularly those related to their HIV and other SRH needs (KIIs with DOH, UNESCO, UNFPA, USAID, SANAC, GIZ, Soul City Institute, Youth Plus South Africa [Y+SA], November-December 2017). Some key informants explained that HCWs, who are usually from the local community, and many of whom are parents themselves, are concerned about the multiple risks faced by adolescent girls and young women, and want to protect them (KII with Democratic Nursing Association of South Africa [DENOSA], November 2017). However, their approach is often experienced by young patients as being judgmental and hostile, and thus, has the effect of deterring them from accessing services. Key informants described, for example, a general unwillingness by many HCWs to acknowledge adolescent sexuality and, as one result, frequently scolded them when they needed SRH services. Because community-level health facilities are often not regarded as safe or welcoming, and also due to inconvenient opening hours

and long waiting times, young people will delay seeking services with, at times, severe consequence for their SRH and other health needs, including those related to HIV (KIIs with DENOSA and Soul City Institute, November 2017).

Additional challenges raised by key informants were similar to those experienced by PLHIV and other key and vulnerable populations (see **Section 4.4.3**, above). For example, problems with security guards were mentioned numerous times for their practice of 'screening' service users at facility gates, ostensibly to ensure that they went to the right area of the facility for their health need. Younger service users were clearly deterred by this invasion of privacy and, in some cases, were turned away when it was discovered that they required contraceptives and termination of pregnancy services. Others were chased away because of their age, because they were late for an appointment, or because they lacked identity documents (KII with Soul City Institute, November 2017).

Other challenges with privacy and confidentially were also raised. Key informants described examples where youth in communities where the HCWs were known to parents, particularly in rural areas, had information such as their HIV status reported to parents without their consent (KII with Lovelife, December 2017). The intention was not thought to be malicious: HCWs in their protective role thought they were helping these adolescents and young people by informing their parents so that they could offer them appropriate support. Nevertheless, due to the taboos around adolescent sexuality, and the fact that there is not a tradition of discussing sexuality openly within families, many of these individuals did not want their parents to know that they were sexually active. Fear of having their confidentially breached was a strong deterrent to using the services at their local clinics (KIIs with GIZ and UNESCO, November 2017). Often, individuals preferred using clinics far away from their own communities, despite the financial burden this involved (KII with Y+SA, November 2017).

Regarding knowledge about the rights and entitlement of adolescents to access SRH services, some key informants were of the view that many HCWs were unaware of the country's laws and policies in this regard, or else they ignored these rights if they conflicted with personal beliefs. For example, some key informants gave accounts of adolescent girls being denied HTS or STI services by HCWs and being told to come back with their parents (KII with SANAC, November 2017). While some other (adult) key informants held the view that adolescent girls and young women were generally themselves not aware of their rights, interviews with peer educators working directly with young persons contradicted this. These individuals stated that this group was in fact very knowledgeable about their SRH-related rights and entitlements but were unable to hold HCWs to account for imposing barriers because of socio-cultural norms around 'respect' for adults (KII with Y+SA, November 2017). There are further challenges regarding how some of these rights are defined within the law and policy context for adolescent SRH. There are discussed below.

4.4.5.2. Contradictions in SRHR laws and policies for adolescent girls and young women

The assessment found that the law pertaining to age of consent to medical procedures, including HIV services (*Children's Act*), contradicted the law pertaining to the age of consent to sex (*Sexual Offences Act*). For example, a girl aged 12 years could consent to termination of pregnancy, while the age of consent for sexual activity is 16 years. Assessment participants noted that this contradiction has led to a misalignment of policies and confusion or obstruction on

the part of HCWs in providing adolescents, particularly girls, with needed services (KIIs with DOH, UNESCO, UNFPA, SANAC, GIZ, Soul City Institute, Y+SA, November-December 2017).

For example, key informants gave accounts of how HCWs shouted at and humiliated adolescent girls or young women who required termination of pregnancy services. Some of them neither provided these services nor referred patients to other healthcare facilities where they were available (as they are required to do by law). Due to such barriers, as well as fears about breach of confidentiality, some individuals relied on 'backyard abortions' which could result in fatalities. This violated their rights in that they were also unable to get HIV, legal and psychosocial support services. These things also contributed to a more general reluctance for adolescent girls to use health services, including those related to HIV (KIIs with DOH, UNESCO, UNFPA, SANAC, GIZ, Soul City Institute, Y+SA, November-December 2017).

With regard to protections against SGBV, key informants working with adolescent girls and young women noted that, on the one hand, DBE policies around SGBV were protective of the human rights of this group. However, on the other, it was noted that, at school level, there were obstacles to the full implementation of these policies, because of conservative norms among teachers, parents and learners themselves regarding sexually active adolescents. It was also stated that attitudes of school governing boards were similar and that this contributed to inconsistencies in the implementation of such policies (KIIs with UNESCO, UNFPA, SANAC, Soul City Institute, Y+SA, November-December 2017).

In relation to this last observation, despite the DBE's HIV/TB/STI Management Policy, key informants also noted that the provision of HIV prevention and treatment services was still being hampered by some school governing boards who argued that it was not the core function of schools to provide SRH services for learners (KIIs with DBE, DOH and SANAC, November 2017). For example, according to one key informant, in Gauteng, condoms were not being distributed in schools. Furthermore, it was stated that some schools chose to interpret the Learner Pregnancy Management Policy in such a way as to punish learners for falling pregnant, a practice which fuelled stigma and discrimination around teenage pregnancy, deterred learners from returning to school after having given birth, and increased school dropout rates. Similarly, some school governing bodies were reported to prevent or modify the content of the DBE-mandated Comprehensive Sexuality Education (CSE) curriculum which was not aligned with their moral values. An example was given of governing bodies which had removed content dealing with sexual orientation and gender identity (KIIs with DBE, DOH, UNESCO, UNFPA and SANAC, November-December 2017).

Finally, across a number of key informants, it was felt that, despite the progressive policies supporting adolescent SRHR, the broader socio-cultural environment deterred learners from reporting cases of sexual abuse and violence, and therefore from receiving the necessary health, social and legal services, including HIV services, to which they were entitled. In an environment where it is commonly reported that (predominantly male) teachers engage in sex with learners, including exchanging 'marks for sex', learners apparently feared that being identified as sexually active would cause them to be labelled as promiscuous, leading to being bullied and ostracised (KIIs with DBE, DOH, UNESCO, USAID, UNFPA and SANAC, November-December 2017).

4.4.5.3. Gaps and challenges in the response to SGBV

Sexual violence in South Africa has been described as having reached epidemic proportions (Joyner, 2016). The prevalence of rape, and particularly multiple perpetrator rape, is unusually high in South Africa (Jewkes et al., 2012). Rape is part of a continuum of sexual violence, occurring against a background of entrenched stigma against persons based on their sexual or gender orientation, gender identity or bodily diversity, highlighting such persons' ongoing experience of harassment, discrimination and sexual and physical violence (Joyner, 2016). The report of the United Nations Special Rapporteur on Gender-based Violence, based on her visit to South Africa in December 2015, acknowledged the country's progressive constitution, legislation and policies to deal with SGBV (Simonovic, 2016). However, she stated unequivocally that SGBV is unacceptably pervasive, revealing systematic violation of women and children's human rights across South.

Commentators, activists and researchers have extensively analysed the roots of sexual violence in South Africa, with many observing that the armed struggle against apartheid and the violent backlash and suppression that followed have led to a normalisation of violence, including sexual violence, in South African society. This 'normalisation' is undoubtedly one of the factors that has led to a reluctance to report or seek assistance and support following rape, from police, health care workers, or other services providers. Research conducted in Gauteng province in 2010 found that only one in twenty-five women who had ever been raped had reported the rape to the police (Machisa et al., 2015). A survey by Médecins sans frontières (MSF) in the Bojanala district of North-West Province found that, while one in four women interviewed had been raped at some point in their lives, only 5% had every sought medical care in the aftermath (MSF, 2017).

While the links between SGBV and risk and vulnerability to HIV infection have been extensively investigated for more than a decade, fewer efforts have explored its impact on access and uptake of HIV services. In a recent synthesis of 'what is known' about the phenomenon of SGBV and its links to HIV across South Africa, Jewkes (2016) notes that, for example, although PEP is available for survivors, uptake is low because only one out of 13 women chose to report violence against them. Furthermore, for those who do take PEP, adherence rates are low due the compounded stigma around rape as well as HIV infection. For HIV-positive survivors, key questions remain regarding impacts on linkage and retention in HIV care, and, particularly for women experiencing intimate partner violence (IPV), retention in PMTCT programmes as well as care for exposed infants. What is known from other research not specific to SGBV is that poor mental health does affect retention in HIV care and, to the extent that HIV-positive survivors of violence also experience poor mental health, this will likely negatively affect retention in HIV services.

While largely concurring with these findings, key informants who addressed SGBV and its effects on access and uptake of HIV services also highlighted current challenges with reporting these crimes (KIIs with South African Police Services [SAPS], National Prosecuting Authority [NPA], Thohoyandou Victim Empowerment Programme [TVEP], NACOSA, November-December 2017). Delays in seeking medical or legal assistance for SGBV also delay access to critical HIV interventions such as PEP. In this regard, at the level of police services in communities, where individuals must go to report SGBV crimes and to seek access to services, assessment participants working with adolescent girls and young women, and with key populations, expressed many concerns (KIIs with ANOVA, TVEP, NACOSA, November-December 2017). A common sentiment was that there was no point in reporting SGBV as police were

either unable or unwilling to pursue such cases. This sentiment was further fuelled by media reports of police corruption and ineptitude.

Some of main concerns raised were that most police officers were male and, whether directly or indirectly, they were sometimes insensitive or inappropriate in their handling of individuals who were reporting SGBV by, for examples, suggesting that adolescent girls or young women helped to cause the assault through their dress or behaviour. Other factors also operated as deterrents, including a lack of privacy in some police stations and the fact that not all stations have Victim Empowerment Units (KII with SAPS, November 2017). Within the justice system, further challenges to successful prosecution of SGBV cases were highlighted. These included poor and overstretched forensic services, the long time it takes for legal cases to be heard and resolved in South Africa, the frequency with which alleged perpetrators are granted bail, and lack of support and protection for survivors (KII with NPA, November 2017). All of these barriers contribute to the low rates of prosecution for rape which have been reported: a recent study found that only 8.6% of a sample of rape cases surveyed resulted in a guilty verdict (Machisa et al., 2017).

As a result, according to key informants, cases of SGBV were not reported and survivors denied themselves not only legal redress but access to critical health services such as PEP. Finally, poor training of Police Officers in the *Domestic Violence Act* and *Sexual Offenses Act* protocols was said to result in sexual assault survivors being either sent away or having their cases compromised (KII with Soul City Institute, November 2017). A number of assessment participants did state, however, that there were ongoing consultations within the Justice Cluster to address many of these issues (KII with SAPS, NPA, November-December 2017).

4.4.5.4. Other human rights barriers based on gender

The assessment identified other gender-related barriers to HIV services. Key informants working with LGBT constituencies, particularly lesbian, bisexual and other women-having-sex-with-women, as well as with transgender men and women, drew attention to the ongoing epidemic of SGBV, including 'corrective rape' and the similar (or greater) barriers these groups face in reporting to the police and in seeking essential medical, legal and psycho-social support services, including PEP (Koraan, 2015).

Individuals working in programmes for PWID reported that around 90% of their service users were male, although according to the size estimation study by Scheibe et al. (2016) 40% of PWID in South Africa are female. To explain this gap, key informants were of the view that current (limited) programmes for PWID were not well-informed about or designed for the specific circumstances and needs of female PWID (KIIs with OUT and Right to Care, November 2017). They described, for example, how female PWID were less likely to be homeless, and therefore less visible. Female PWID were more likely to be housed, in their view, as they often would exchange sex for drugs and shelter. Many stayed with boyfriends, pimps or drug dealers who acted as gatekeepers, and could block access for outreach teams, or block women from attending health services. Although the presence of female sex workers who inject drugs was known (in particular, in Gauteng), they were not being adequately accessed by either PWID or sex worker programmes (KII with SWEAT, November 2017).

Female migrants were thought to face several barriers to access and retention in HIV services. They were more likely to work in the informal economy and when employed, more likely to work under precarious or exploitative conditions (KIIs with Passop and IOM, November

2017). They were also more vulnerable to human trafficking and, in such situations, were likely to be denied access to any health services. They were also more likely to be controlled by male partners. These same informants stated that these barriers were more pronounced when migrants were undocumented.

While to this point, the assessment has identified a number of on-going, substantive human rights barriers to HIV services in South Africa, it has not yet addressed the extensive nature of current efforts to address and remove the barriers. These efforts are described in the next section.

4.5. Efforts to address and remove barriers

4.5.1. Overview

Compared to other countries on the continent, South Africa has a large and independent civil society sector, including organisations which work around human rights, gender and social justice; which are a reservoir of expertise and innovation; and, which are actively involved in accountability monitoring and advocacy. However, many of these CSOs and other entities do not always articulate the link between human rights and HIV in their work. Within the civil society HIV sector, there was a general sentiment that there was a great discrepancy between well-resourced, or so-called 'blue chip,' organisations, which were viewed by some as being able to attract generous donor funds and well-qualified staff, but were seen by critics as being out of touch with the needs of communities -- and the smaller, community-level CSOs. These latter groups held a wealth of relevant community knowledge and access to social networks, but lacked the skills and funds to implement the necessary type and scale of activities. The perception was that the former category of organisations was either less able or less willing to tackle human rights barriers, because they were donor- and target-driven, while the latter category was more prepared to address human rights barriers, albeit typically on a smaller scale, but lacked sufficient technical or financial resources in order to do so.

Partly for these reasons, a number of the interventions which are described below have not been explicitly designed to address human rights barriers to access, uptake and retention in HIV services. However, they are included here as they fit the conceptual frame of this assessment, in that the interventions contribute in some way to addressing and removing human rights or gender related barriers to HIV services. In addition, some of the interventions do not fit neatly into one of the seven programme areas which have been used to initially structure the analysis. They have components from more than one programme area and, for this reason, may be described in more than one section.

4.5.2. Stigma and discrimination reduction

To put this section in context, it should be noted that social epidemiological research into the complex, dynamic and iterative mechanisms by which stigma and discrimination act as macro-structural determinants of HIV, and as barriers to access to HIV services, is a developing field. Although a growing body of evidence is showing how stigma and discrimination impact on the HIV prevention, treatment and care cascade, there is still a lot that is not well understood (Shannon et al., 2015; UNAIDS, 2017). The evidence base for what works to reduce stigma and discrimination is relatively recent, but growing. Broadly speaking, peoplecentred, multi-layered, community-led structural interventions, as part of combination HIV

programmes, are acknowledged as being essential and effective in reducing stigma and discrimination (Shannon et al, 2015; UNAIDS, 2017).

Against this background, examples of current approaches used by stakeholders to address stigma and discrimination are described below. Efforts are being implemented at different levels and scales, including some broad national efforts, as well as focused interventions aimed at specific populations and sub-populations, to address external stigma, self-stigma and to build personal resilience and agency in local communities.

On the *national* level, the assessment identified the following:

- SANAC has shown leadership in coordinating a programme to reduce stigma which had three core components: 1) a partnership with Legal Aid South Africa to train lawyers and paralegals to provide legal representation and advice to people who have experienced HIV-related stigma and discrimination linked to a national, toll-free helpline; 2) piloting of a community level anti-stigma programme in the Eastern Cape, using a modification of the Prevention in Action community-based programme to reduce GBV; 7 and 3) a national communication campaign designed to challenge stigmatising attitudes, build understanding of PLHIV, and market the Legal Aid South Africa service (SANAC, 2015). Although funding for components 1) and 3) of this project has ended, component 2) has been continued, as described below.
- The Community Anti-Stigma Programme is implemented by the Soul City Institute (a Global Fund Principal Recipient) through a network of implementing partners in seven districts. The programme design is informed by the findings of the PLHIV Stigma Index Survey, and lessons learnt from the Eastern Cape pilot. The programme is aimed at PLHIV, particularly young people. In the programme, CSOs are trained on community mobilisation approaches to stigma reduction so that they can go on to implement antistigma programmes that are tailored to their communities. These interventions include community action plans which consist of activities that increase knowledge about HIV, and that foster acceptance of PLHIV and increase their access to HIV and TB services. Although no structured evaluation has been conducted, from the perspective of Soul City Institute the level of community engagement has been high and many PLHIV have come forward to participate in these initiatives. However, it has not yet been determined whether the programme has an effect on reducing self-stigma (KII with Soul City Institute, November 2017).
- The two largest PLHIV organisations, **Treatment Action Campaign (TAC)** and the **National Association of People Living with HIV and AIDS (NAPWA)**, address stigma and discrimination in several ways. Firstly, their very existence as collectives of out, vocal, and visible PLHIV have been key in reducing stigma and discrimination from the very elevated levels during the era of AIDS denialism in the 1990's to the moderate levels recorded in the PLHIV Stigma Index Survey. Secondly, these networks provide critical mechanisms for social support and solidarity amongst PLHIV which reduce levels of self-stigma. Thirdly, network members participate actively in advocacy, decision-making and accountability monitoring at all levels of government. Finally, the networks are consulted in the planning and implementation of national anti-stigma campaigns, such as the

⁷ For a description of this approach, see: http://www.saferspaces.org.za/blog/entry/prevention-in-action-working-together-to-prevent-violence-against-women

SANAC project described above.

- **SWEAT** undertakes several projects, campaigns and activities which contribute to the reduction of stigma and discrimination against sex workers country-wide. These include: engagement with the media and individual journalists on non-stigmatising reporting, using the *Sex Workers and Sex Work in South Africa: A Guide for Journalists and Writers*, developed by Sonke Gender Justice; training and supporting sex workers to speak to the media and on public platforms; visible media presence and extensive use of social and traditional media to address stigma and discrimination; public activities and protests, including the Say Her Name Campaign (to highlight murders of sex workers); and marking the International Sex Worker Rights Days on March 3 and December 17 each year.
- ANOVA coordinates the We the Brave campaign, an online campaign to promote gay men's sexual health in a non-judgemental, sex-positive, youth-friendly way, funded by the Elton John AIDS Foundation.9
- The **StepUP Project** for PWID, implemented by TB/HIV Care Association and OUT, in three cities in South Africa (Cape Town, Tshwane and Durban) is a best practice example of a harm reduction programme, which meaningfully involves PWID community members. ¹⁰ The programme model integrates several activities which collectively contribute to reducing the severe stigma and discrimination towards PWID, including peer education, psycho-social support, supported referrals to health services, community mobilisation, sensitisation of stakeholders, and advocacy.
- Key population constituencies address stigma and discrimination through movement-building and mobilising their members to raise their concerns publicly, to participate in decision-making processes, and to 'put a human face' to stigmatised and marginalised populations in the country. These movements include the **South African Network of People Who Use Drugs (SANPUD)** and the **Sisonke** sex workers' movement.
- **SAFAIDS' Champions Programme** identifies, trains and mentors influential community, religious and traditional leaders to act against stigma and discrimination in their respective spheres of influence. This programme is being implemented in eight countries in the SADC region, as part of the KP REACH grant, but in South Africa, has only been implemented in North West and Limpopo Provinces.

At a *local and community level*, some programmes are specifically conceptualised to mitigate against stigma and discrimination, while others are not, although stigma reduction may be one objective within a broader intervention. These broader interventions include community systems strengthening activities, and key population-friendly health services. Some examples of these efforts are:

 Several community-based, LGBTI-led organisations address stigma and discrimination as a core pillar of their work. A main activity which contributed towards reducing stigma and

⁸ Available at: http://www.genderhub.org/get-in-the-know/resource-library/sex-workers-and-sex-work-in-south-africa-a-guide-for-journalists-and-writers/

⁹ See: http://www.wethebrave.co.za/

¹⁰ Since the assessment was completed, this initiative has been renamed the HarmLess Project.

discrimination was the provision of safe spaces for LGBTI people to come together to share their concerns, provide mutual support and counselling, support referrals to LGBTI-friendly services, and to be a platform for collective advocacy. These organisations included OUT LGBT Well-being in Pretoria/Tshwane, Durban LGBTI Centre, Pietermaritzburg Gay and Lesbian Centre, Triangle Project in Cape Town, SO-HACA in Soweto, and projects by ANOVA, including the Boithatho Project in Mbombela, Mpumalanga, and the Handsup#4Prevention Project in Joe Gqabi District, Eastern Cape, among others.

- Similarly, the 14 grantees under the Global Fund-supported **National Sex Worker Programme** are continuing to implement Creative Space workshops in the 13 districts where the programme operates. These activities have multiple benefits similar to those for the LGBTI safe spaces interventions described above. The workshops are supported by a Creative Space Manual which includes components on human rights.¹¹
- As an example of interventions for transgender women, **SHE** in East London implements a range of innovative, creative activities and campaigns aimed at reducing stigma and discrimination. These include: 'In Her Shoes', an event celebrating trans beauty which is used as a platform to raise awareness about transgender health (especially HIV) and human rights; and, 'In Her Own words', an activity which documents the life stories of transgender women to raise awareness and to improve understanding and acceptance of this form of gender identity and expression. **GenderDynamix** implements a range of similar activities in Cape Town. Both of these organisations also participate in national, regional and global level advocacy activities.
- Several projects which addressed **stigma and discrimination reduction at universities** were documented. Of these, a number were continuing the legacy of the programme to support LGBTI students within higher education, funded by Global Fund through **NA-COSA**, which ended in 2016. An evaluation of this programme found that it had had a positive impact in many areas, including knowledge about sexual health; acceptability of campus health services; and, a reduction in interpersonal and institutional stigma. Interviews with key informants who had been involved with this programme found that, while some of its impacts at the institutional and policy levels had been sustained, other programme activities to address stigma and discrimination (including internalised stigma) were no longer functioning (KIIs with LGBT representatives from University of Limpopo and DUT, November 2017).
- To address stigma and discrimination against foreign migrants, Passop conducts out-reach and public education and awareness activities, such as 'Meet an Immigrant,' and engages with health facilities to advocate for migrant access to health care, including HIV services. Several social justice organisations, such as Sonke Gender Justice and TAC have participated in campaigns to combat xenophobic discrimination and violence against foreign migrants, including promoting their rights to access to HIV services.
- The network of Community Advice Offices, under the umbrella of the National Alliance for the Development of Community Advice Offices (NADCAO), conduct

37

¹¹ The manual is available at: http://www.sweat.org.za/wp-content/uploads/2016/02/Creative-Space-Manual-1.pdf

community dialogues to promote inclusiveness, and to reduce stigma and discrimination, including against LGBTI, migrants and youth. The assessment did not ascertain how many advice offices conducted these dialogues, however, and to what extent they addressed HIV-related stigma and discrimination. These offices also offer legal services, which is discussed at **Section 4.5.6**, below.

Across these collective efforts, however, there are some important gaps:

- Although government and civil society stakeholders have a basic understanding of how stigma and discrimination manifests itself, more learning is required to develop a more sophisticated, evidence-informed analysis. Linked to this, there is also inadequate understanding of including how to conceptualise, implement and evaluate multi-pronged stigma reduction programmes, which operate on different levels. In particular, the drivers, manifestations and potential solutions for self-stigma are still not adequately acknowledged and understood.
- There has been insufficient research or evaluation of stigma reduction programmes at all
 levels and across all modalities of programme design and implementation. It is also not
 well understood whether anti-stigma projects of limited duration produce sustainable
 change, including beyond a three-year grant cycle, for example.
- Because the PLHIV Stigma Index Survey found that stigma and discrimination levels were 'only' moderate and not as severe as may have been the case in the past, there is a tendency for complacency. Furthermore, those involved in conceptualising and planning programmes find it easier to respond to 'worse case scenarios,' such as direct discrimination in employment or health services, where the problem to be addressed is more obvious and clearly understood, rather than to work to address more complex issues such as the ongoing burden of self-stigma amongst PLHIV.
- Although the Soul City Institute's anti-stigma campaign aligns with the recommendations
 emanating from the PLHIV Stigma Index Survey in prioritising the three provinces with
 the highest stigma levels, similar stigma reduction campaigns are not being implemented
 in all provinces.
- Funding for HIV programmes puts a heavy emphasis on biomedical interventions (HTS, distribution of commodities, ART, for example) meaning that more holistic programme models, with components which address self-esteem, social support, and community systems strengthening, receive less priority and are more often 'squeezed out' of funding requests.
- Several key informants expressed concern for the high burden of mental illness in South Africa, including depression and post-traumatic stress, and particularly amongst key populations. However, it was felt that mental health support was lacking at public health facilities, and that HCWs providing HIV-related services were poorly equipped to recognise, diagnose and provide appropriate counselling support or referral for treatment.
- Within the DOH's HTA programme, which provides conditional grants to NGOs to provide

HIV prevention services to populations in these areas, the programme's strategy for accessing key populations, including with interventions to address human rights barriers to HIV care, is not well-defined. It was felt that the programme's strategy was not aligned with best practice models for HIV prevention with key populations.

To strengthen the reach and impact of work to reduce HIV-related stigma and discrimination, a comprehensive approach should include the following:

- Establish a national Stigma and Discrimination Reduction Working Group to develop a national Stigma and Discrimination Reduction Strategy. The Working Group should be a multi-stakeholder structure consisting of representatives of relevant government departments, key and vulnerable populations, senior religious and traditional leaders, communications experts, and academic experts on stigma and discrimination. The Strategy should contain, at a minimum, the elements described below.
- Develop a national stigma-reduction communications campaign. The campaign should be evidence-informed and co-created with representatives of key and vulnerable populations. The campaign should use multiple modalities, and should deliver new messages, in new ways. There are useful lessons to be learnt by the communications work done over the past three years as part of the KP REACH programme (KP REACH, 2018).
- Scale up interventions which support anti-stigma champions. Two levels of champions must be created: 1) a small group of high profile leaders and celebrities to participate in the communications campaign; and 2) a larger group of community-level, traditional and religious leaders with a focus on rural areas where stigma is more entrenched.
- Strengthen the technical and operational capacities of key population and PLHIV networks to deliver integrated programmes to address stigma, discrimination and violence against their members at community level. The assessment encountered a number of community-led entities working to implement these types of activities but struggling with inadequate technical and operational capacity to scale-up and sustain their efforts.
- Scale up the Community Anti-stigma Programme to an additional ten districts, taking into account learning from the current efforts. The ten new districts should be selected in consultation with key stakeholders and target additional areas of the country where HIV stigma and discrimination remains high.
- Strengthen psychosocial support programmes for PLHIV and key populations in communities. This should be done by 1) creating posts for professional counsellors at organisations providing services; and 2) providing a cadre of peer educators with advances skills in counselling and support. Deploying registered social workers or psychological counsellors is one strategy that should be considered as well as supporting peer educators to complete training such as the Lifeline Personal Growth and Basic Counselling courses.¹²

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¹² Lifeline has a national footprint, with 26 branches in South Africa, in all provinces. Several Lifeline branches have been or are currently SR's in Global Fund key and vulnerable population programmes, and

- Strengthen the HTA programme to ensure that it can fulfill its mandate to reach key populations with HIV prevention services. This should include provision of technical support to review its model so that it is more aligned with best-practice approaches, tailored for the current South African epidemiological and social-cultural context, and so that it integrates strategies to reduce stigma and discrimination.
- Support rapid assessments, surveys and evaluations to inform stigma reduction interventions. This should include repeating the PLHIV Stigma Index Survey but with changes to the design and the participant recruitment strategy so that it can also measure stigma and discrimination towards PLHIV who are members of key populations.
- Conduct a national situational assessment on access to HIV services for foreign migrants and develop an action plan to address the results. The assessment should include foreign migrants who are members of key populations, especially LGBTI and sex workers. While this assessment has made some tentative conclusions that serious human rights barriers to services exist for these groups, more comprehensive information is needed on an urgent basis.

4.5.3. Training of health care workers on human rights and medical ethics

The assessment identified several examples of projects which train HCW on human rights and medical ethics, as well as on the more specific health needs of key populations. These efforts mainly cover competencies in key-population-specific clinical needs, and/or general sensitisation on stigma and discrimination. Some were more structured than others, with formal curricula, defined training procedures and accreditation systems. Others were more localised, informal or ad-hoc. Studies, such as NACOSA (2016), have documented the extent to which health facilities which are deemed as being sensitised are valued and preferred by key population members.

Examples of these projects include:

- ANOVA Health's two MSM Centres of Excellence (Ivan Toms in Cape Town and Yeoville Clinic in Johannesburg) serve as sites where mentoring is done with DOH clinicians and other HCWs to develop their expertise in men's health. The project also supports capacity-building for a network of DOH facilities country-wide. In addition to training on clinical care and psycho-social support, the approach includes sensitisation training for all staff at the facility (general and clinical) to create an MSM-friendly environment in facilities. As of the most recent information, ANOVA has supported 67 primary health care facilities in the public sector to be certified and promoted by them as competent to provide services to MSM and other members of LGBTI constituencies (EHPSA, 2017). One pre-post-training evaluation has been conducted of their training and noted positive shifts in knowledge and attitudes (Scheibe et al., 2017b). However, no longitudinal analysis has been conducted to measure changes over time in service provision and service uptake.
- **SWEAT**, with funding from the Global Fund, provides sensitisation training for health

thus are attuned to the needs and challenges of these populations. See, for example: http://www.life-linejhb.org.za/index.ashx

facility staff in 13 districts. The main objectives of the intervention are to sensitise HCWs to sex workers' health needs, and to build an understanding of how stigma and discrimination deter sex workers from accessing health care, including HIV services. The evaluation of the Phase II of the National Sex Worker Programme, which ended in 2016, found a steady improvement in access to health care, linked to an improvement in HCW's attitudes towards sex workers which stemmed from continuous engagement with facilities by local sex worker constituencies, and formal sensitisation training.

- OUT LGBT Well-Being also undertakes advocacy and training of service providers to serve LGBTI constituencies regarding stigma and discrimination within health facilities (OUT, 2014). In 2015, it was reported that 245 service providers from public health clinics in the Tshwane metro area participate in the training (OUT, 2017). No more recent information was available.
- International Training and Education Center for Health (I-TECH), with funding from CDC, is developing a key population sensitisation manual for all HCW. The manual and the training linked to it are currently being piloted in KZN province. There is a plan to expand the programme country-wide based on the results of the pilot phase once it is completed.
- Only one intervention from within the nursing sector was documented. **DENOSA** offers a 2-day training for nurses on values clarification and dealing with gender and sexuality. The training, using the WHO *Health Workers for Change curriculum*, is structured around taking HCW on a self-reflection journey aimed at helping them to deal with their own prejudices around sexuality (mainly around adolescent sexuality) in order to enable them to deliver a more professional service based on national laws and policies. ¹³ It also has a life skills component that aims to help HCW to deal with stressful working conditions, cope with stress in their personal lives, and support each other in stressful situations.
- A number of CSOs are involved in providing training to students in health sciences on aspects of diversity, including sexual orientation, gender identity and expression. For example, **Triangle Project** does lectures for students at the University of Cape Town and the University of the Western Cape. OUT LGBT Well-Being's **StepUP** works with medical students at the University of Pretoria to train them in the harm reduction approaches for PWID, and to provide them with placements at the organisation, as part of the university's **Community Oriented Substance Use Programme (COSUP).**¹⁴
- With regard to PLHIV, and the provision of HIV services in public health facilities, TAC supports an 'adopted clinic' intervention. In this model, TAC members in communities forge relationships with local health facilities to monitor and work towards improving the quality and reliability of HIV services. Often what this involves is using the advocacy capacity of TAC to work on health facility challenges, such as under-staffing, poor infrastructure, or chronic stock-outs of essential medicines. As part of the relationship, HCWs are full sensitised and support to offer quality and stigma-free HIV services. TAC also takes the opportunity to mobilise surrounding communities regarding their rights to health and

¹³ See: http://apps.who.int/iris/bitstream/handle/10665/65540/TDR_GEN_99.1.pdf?sequence=1&isAllowed=y

¹⁴ See, for example: http://www.up.ac.za/en/family-medicine/news/post_2603216-cosup-a-medical-students-view

health services. There has been no formal evaluation of this programme but stakeholders familiar with it noted that the aspect of engagement and partnership (as opposed to public criticism) was very important for securing needed changes to HCW attitudes.

• With regard to interventions within higher education to reform and improve curricula of health care workers (a recommendation which was repeatedly voiced by key informants), the **Higher Education and Training HIV/ AIDS programme (HEAIDS)** commissioned research in 2010 on the integration of HIV into curricula in institutions of higher learning, which included a component related to the areas discussed in this report, such as competence in addressing diversity, gender and sexuality (HEAIDS, 2010). The findings identified a competency gap in this area and, as a result, HEAIDS partnered with the **Centre for Sexualities, AIDS and Gender** at the **University of Pretoria** to develop a 2-day workshop called **Critical Diversity Literacy** which was implemented in onceoff sessions in 9 universities. In an evaluation report, the workshop was found to have created shifts in thinking, as well as in academic practice (HEAIDS, 2017). This kind of intervention can lay the ground work for curriculum review and transformation. While the workshops were mainly implemented with education faculty staff, the model could just as well be targeted with health care faculty staff and in nursing colleges.

Across these efforts, however, the following gaps were identified:

- There did not seem to be coordination and harmonisation of existing efforts across different donor-funded programmes for key populations, leading to fragmentation and inconsistencies in quality and effectiveness.
- Training on key-population-competent service delivery generally takes place only in the
 districts where there are existing CSO-provided key population programmes, leaving other
 parts of the country where there are also key populations in communities without this important intervention.
- The assessment found no coordinated efforts to reform or improve basic curricula in order to equip HCW in their pre-service training with the necessary skills to provide health care which respects the human rights of all patients. While an assessment of nurses' attitudes as barriers to care done by DOH was mentioned by key informants, information on the assessment report or any subsequent actions could not be found.
- In-service training interventions, where they occurred (and with the exception of the ANOVA model), were focused on nurses and rarely had a 'whole clinic' approach. Thus, the non-clinical staff at facilities, such as clerks, cleaners, or security guards, were usually excluded.
- Besides the sensitisation training model implemented by ANOVA, there is generally no comprehensive or routine tracking of changes in knowledge, attitudes or practices amongst HCWs regarding provision of services to PLHIV and other key or vulnerable populations.

A more comprehensive approach to improving the skills and motivation of HCWs regarding human rights and medical ethics should, therefore, include the following:

- Scale up the implementation of the Health Workers for Change training to cover more health facilities. The DOH with DENOSA should lead this effort. The Regional Training Centres can be used to deliver the training. Non-clinical staff in facilities should be included in such trainings.
- Deliver key population sensitization training (using the I-TECH manual) through the Regional Training Centres to improve the coordination of this training and to ensure country-wide coverage.
- Equip key-population-led CSOs with the technical and operational capacities to provide district-level sensitization training and mentorship for health facilities. There should be two types of intervention in this regard: 1) a year-long mentorship and engagement with a health facility leading to a form of accreditation as a key-population-friendly service point; or 2) periodic sensitization workshops and active local engagement where a one-year approach is not feasible (modeled on the approach of SWEAT, for example, as described above).
- Strengthen and scale-up local collaborations between health facilities and CSOs, especially those that are key-population-led, for programme components such as outreach, screening and referrals, peer navigation, or adherence support. Such partnerships can improve HCWs attitudes and commitment to providing stigma-free services. Such partnerships can be a logical outcome of the collaborative approaches described in the previous activity.
- Review training curricula for all health and social services professions to assess whether training curricula are adequately supporting the development of competencies in diversity, sexuality, gender and human rights. Based in the results of the review, develop a national action plan to address gaps.
- Scale up provision of Critical Diversity Literacy training to staff in relevant departments of universities, colleges and other health training institutions. This can prompt departments themselves to review their training programmes and can also prepare the way for needed curriculum changes once they are identified.

4.5.4. Sensitisation of law-makers and law enforcement agents

Current efforts to build the capacity of the law and justice sector on their role in promoting and protecting HIV-related human rights and gender equality include the following:

- The **DOJCD** and **SAPS** have taken active roles to address violence against LGBTI constituencies in South Africa, and to promoting non-discrimination and equality down to community levels. For example, the DOJCD has released a *National Intervention Strategy for the LGBTI Sector 2014-2017* for the purpose of preventing and responding to violent crimes against these constituencies (DOJCD, 2014a). As part of the strategy, a National Task Team has been created (DOJCD, 2014b). However, one member has noted recently that, as of 2016, meetings of the Task Team were postponed indefinitely (OUT, 2017).
- The previous Minister of Police spoke out on violence against LGBT people, reiterating SAPS' obligation to respond to all people who have experienced violence according to its

national protocols.¹⁵ The SAPS 2015/2016 annual report lists a number of activities related to training and capacity development, as well as for improving service provision to protect LGBT constituencies against violence (SAPS, 2016). A round table meeting held before the IAS 2016 Conference in Durban, between law enforcement, criminal justice and HIV programmes working with key populations, is seen as having laid the ground for closer collaboration between these partners (IAS, 2016).

- A recent study by Scheibe et al (2016) critically examines approaches to engaging with police to reduce human rights violations, and argues that antagonistic approaches which blame or demonise the police may be counter-productive, and that approaches which seek common ground and joint problem-solving are more effective. The article cites a process wherein the **Urban Futures Centre** at DUT forged a collaborative relationship with police units tasked with policing sex work and drug use in the city of Durban. The collaboration led to meetings between key population CSOs and the police, which over time led to greater mutual understanding, and a positive shift in police attitudes and practices towards these groups.
- In the same vein, civil society engagement with the law enforcement sector led to a Police and Human Rights Dialogue in 2017, hosted by the African Police Civilian Oversight Forum and the SAHRC, to promote constructive dialogue between police, civil society and oversight bodies. The Dialogue resulted in several recommendations. One of the immediate outcomes has been the establishment of two 'point people', one for sex workers and one for LGBTI, within the SAPS national office. Their role is to provide rapid resolution of complaints of human rights violations against these populations.
- As part of the **Hands Off Programme** to address violence against sex workers, funded by Aids Fonds, The Netherlands, a training curriculum to sensitise police officers to the rights of key populations was developed. The *Police Sensitisation Training Manual: A Guide for South African Police Services (SAPS) to the Rights of Sex Workers and the LGBTI Community* has been piloted in training sessions with 300 police officers.¹⁷ SAPS, SANAC and civil society partners are in discussion to roll it out to police training colleges and to use it for in-service training. SANAC has reported recently that they intend that this engagement will lead to a commitment by SAPS to cease confiscating or destroying condoms, or using condoms as evidence of sex work (KII with SANAC, January 2018)
- Both the **StepUP Project** and the **National Sex Worker Programme** have components that involve working with police in the districts where they are being implemented. This includes proactive work such as sensitisation and community engagement, as well as reactive work such as mediation and representation when individuals are harassed or arrested. The National Sex Worker Programme Phase II evaluation found that in some districts, relationships between sex workers and the police had improved, that there had been a decrease in harassment, and an increase in police protection and responsiveness to sex workers who had been victims of crime (NACOSA, 2016; Stacey et al. 2016). Anecdotally, key informants working with PWID reported more resistance from police, possibly be-

¹⁵ See, for example, https://www.saps.gov.za/newsroom/msspeechdetail.php?nid=12281

 $^{^{\}rm 16}$ The dialogue report is available at: http://apcof.org/wp-content/uploads/police-and-human-rights-dialogue-20-21-april-2017-johannesburg-.pdf

¹⁷ The manual is available at: http://wlce.co.za/wp-content/uploads/2017/02/POLICE-manual-LONG-v3.pdf

cause of the newness of harm reduction programmes. However, some peer educators explained how they discussed the programme with police officers when they met them on the streets, and that, thereafter, these police would not interfere with their work or their clients (KII with StepUP peer educators, November 2017).

- The Asijiki Coalition of organisations advocating for the decriminalisation of sex work
 engages in lobbying and advocacy with parliamentarians and other decision-makers, including advancing public health and HIV arguments.
- A number of LGBTI-led CSOs engage with police stations in their communities to increase awareness of hate crimes, and to improve the handling of SGBV cases. These include the organisational members of the national **Hate Crimes Rapid Response Team** which are the Durban LGBTI Centre, the Pietermaritzburg Gay and Lesbian Centre, and OUT LGBT Well-being in Pretoria. The group contributes to an annual report on *Hate Crimes Against LGBTI People in South Africa* and has recently released a consolidated research report on their monitoring of all hate crimes in South Africa from 2013-2017 (Hate Crimes Working Group, 2018; OUT Right LGBT Well-Being, 2016).
- The NACOSA GBV programme conducts SAPS sensitivity training to strengthen services to survivors of rape and IPV in the five districts where the programme is being implemented. In addition, the sub-grantees under this programme also engage with the police at local levels.

Across these efforts, some gaps remain which include:

- Most efforts were focused on working with the law enforcement sector. The assessment identified no current efforts to work with the judiciary at national or sub-national levels, or with traditional leaders who are often involved in mediating and adjudicating disputes which do not reach the formal justice system.
- While there was consensus between SAPS, DOH and SANAC that certain police practices were problematic in relation to HIV, and that they posed on-going human rights barriers to accessing HIV services, including interfering with ART adherence, all parties also agreed that coordination between the different stakeholders was challenging and inadequate. Concern was expressed that police sensitisation efforts were not reaching the correct level within the police service. It was felt that trainings were targeted either at too high a level, and were not adequately disseminated throughout SAPS, or at too low a level, such that officers felt unable to implement changes without authorisation and support from their seniors. The Police and Human Rights Dialogue, described above, resulted in recommendations to address some of these issues. The assessment did not determine to what extent they were being acted on.
- The Hands Off! police Sensitisation training is promising in that endorsement from SAPS senior level management has been secured. However, full implementation is hampered by lack of resources as well as lack of technical capacity within SAPS to coordinate a country-wide approach.

- No specific efforts were identified that were addressing the lack of access to ARVs and other medication for sex workers, PWID and other detainees while in police cells or while awaiting trial.
- No stakeholders were directly addressing the conflict between HIV policies, such as the NSP, and national laws which criminalise sex work and drug use, for example. Thus, as described previously, police felt they had a legal duty to arrest drug users and sex workers for criminal activities first and foremost rather than to prioritise their HIV and related health needs. Unless this contradiction can be resolved, ultimately through law and policy reform but also through sensitisation and monitoring work with SAPS, a major obstacle to improving access and uptake of HIV services for these groups will remain.
- Finally, aside from the work of Scheibe et al. (2016) and Stacey et al. (2016), the assessment found no other examples of the evaluation of interventions within the law and justice sectors. This is a gap that should be closed.

A more comprehensive approach to equipping the law and justice sectors (including traditional leaders) to be more active and engaged on HIV-related human rights concerns should include the following:

- Undertake a focused assessment on the role of the judiciary and traditional leaders in potentially contributing to barriers to services for key populations and develop an action plan to address the results. The assessment should reach into communities where there is more reliance on traditional justice and conflict mediation.
- Support SANAC to take a lead role to improve senior-level coordination and cooperation between itself, SAPS, DOH, CSOs and other relevant stakeholders in order to strengthen the role of the police in communities in reducing barriers to HIV services. This work could include encouraging SAPS to release a public commitment to ceasing the practice of confiscating condoms from sex workers, or harm reduction commodities from PWID.
- Scale up efforts to bring about positive shifts in knowledge, attitudes and practices of the police regarding key and vulnerable populations and their need for HIV services. In doing this, ensure that sensitization efforts are strategically targeted for sustainability and optimal impact. This includes working towards institutional shifts through more comprehensive, longer-term approaches, while at the same time continuing local-level interventions with individual policing units.
- Continue work to train and sensitise policy-makers, police and the judiciary on the importance of harm reduction for PWID. Balance the emphasis in this work between harm reduction as an HIV prevention intervention, and harm reduction as globally-endorsed human right for all drug users. Also, ensure that there is continued emphasis on the evidence that shows that harm reduction does not encourage drug use.
- Strengthen the operational and technical capacity of local key-population-led CSOs to facilitate and lead 'constructive engagement' interventions with local

police as well as local traditional leaders. While a number of CSOs already do this work they are not sufficiently funded to sustain their efforts long enough to secure permanent change.

• Expedite the establishment of a National Policing Board, as mandated in the National Development Plan. According to the plan, one of the objectives of the National Policing Board should be, "to develop a professional code of ethics and analyse the professional standing of policing, based on international norms and standards."

4.5.5. Legal literacy

Knowledge about human rights in the context of HIV, including for key populations, is generally strong in South Africa. There is a strong tradition of legal and human rights literacy in HIV-focussed and key-population-led organisations across the country dating back to the earliest days of mobilisation around the HIV epidemic. In addition, most key populations programmes have always had a rights literacy component, especially those which are led by or have significant involvement of key population constituencies themselves. Amongst those groups included in the assessment, staff and peer educators of PWID and sex worker programmes had higher levels of human rights knowledge and awareness (presumably linked to the criminalisation of their activities). Of all the key population programmes addressing legal literacy, the **National Sex Worker Programme** had the strongest approach with specific components on human rights education and legal defence integrated within the broader programme design.

Additional efforts are described below:

- Amongst its many activities in support of the rights of public health system users, especially for PLHIV, TAC provides basic training to all of its members (over 8,000) in seven provinces on the science of HIV, TB and related conditions, and about their rights within the healthcare system. This has been part of their community mobilisation model since its inception; however, there has been no recent assessment of where it continues to be useful for all PLHIV. Some TAC members interviewed as key informants noted how it was becoming challenging to recruit new members and some individuals they approached preferred to keep living with HIV part of their private life and felt no need to be part of such structures (KII with TAC Gauteng structure, December 2017).
- Similarly, **NAPWA** has developed the Positive Health Dignity Plan (PHDP) training, which deals with community-initiated and integrated programme design and implementation as part of establishing and enforcing what they call an Advanced Adherence Programme. The training has a strong human rights component.¹⁸
- **Section 27** developed the *HIV/AIDS* and the *Law: A Resource Manual* in 1997 and has updated it over the years. ¹⁹ The manual aims to help PLHIV and those affected by HIV to navigate their way through the law on human rights and discrimination. It aims to assist many different types of people, including paralegals, judges, politicians, trade unionists,

¹⁸ The training manual is available at: https://www.gnpplus.net/assets/web_GNP-PHDP-for-individuals.com-pressedtwice.pdf

¹⁹ The manual is published in book form. For a description, see: http://section27.org.za/2003/06/hivaids-and-the-law-manual/

as well as people offering pre- and post-test counselling for HIV, among others. However, as the HIV has become well-entrenched within the fabric of South African society, key informants noted that demand for the manual had been declining (KII with Section 27, December 2017).

- Legal AID South Africa has an outreach programme. They conduct workshops in specific communities, including in prisons, to inform participants about justice issues, including HIV-related human rights. They also host a weekly radio programme called "Justice on the Airwayes."
- Sonke Gender Justice provides HIV training, education and rights literacy for migrants in Cape Town and Johannesburg. Women's Legal Centre also has a 'Know your rights' project for migrants, which includes the right to health.
- The Love Not Hate Campaign, based at OUT LGBT Well-being, is a joint initiative between six LGBT groups and the US Department of State. As part of the campaign, LGBT individuals who experience discrimination or violence can report these incidents and obtain basic advice and support on how to seek redress (OUT Right LGBT Well-being, 2016).²⁰ The StepUP Project, based at the same organisation, offers a similar process for PWID (Williams et al., 2015).
- Human rights literacy is a core component of the work of the Community Advice Offices under NADCAO. These facilities deal with all rights, including HIV-related rights.
- **Sisonke** has developed a rights-based, self-development curriculum for sex workers. This involves a three-day training workshops by Sisonke members for Sisonke members, where the organisation has branches (Cape Town; Durban; Johannesburg; East London; and, Polokwane). **SWEAT** also implements many rights literacy activities, including distributing a range of rights literacy materials.
- **SHE** provides human rights advice and education to transgender women, including rights regarding HIV treatment, and rights regarding gender reassignment.
- Community based SGBV organisations, such as Masimanyane and Thohoyandou Empowerment Programme (TVEP), hold community workshops on human rights, SGBV, IPV, and workshops for rape survivors. These are also discussed in Section 4.5.8, below.

While this range of activities and approaches is substantial and highly relevant, there are, nevertheless, opportunities to expand and improve legal literacy interventions. Some of the main gaps to be addressed include:

• There was the perception that while legal literacy was important, knowledge of legal entitlements was pointless unless this resulted in the realisation of these rights. There was frustration and despondency that South African's wide ranging Constitutional rights 'looked good on paper' but were aspirational in nature, and that there were deep systemic

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²⁰ See http://www.out.org.za/index.php/what-s-hot/services/436-love-not-hate

obstacles to these rights becoming a reality.

- There appeared to be no standard content for legal literacy interventions.
- There have been no evaluations of activities to determine which approaches are more effective and, more importantly, whether such training results in more PLHIV or individuals from key population groups pursuing legal or human rights claims.
- While there is an active, well developed human rights and social justice sector within civil society, there was perceived to be a disconnect between this sector and the HIV sector.

A more comprehensive approach to improving legal and human rights literacy amongst PLHIV and key population constituencies should include the following:

- Support PLHIV networks and key-population-led CSOs to scale up activities
 to improve knowledge regarding HIV-related human rights for individuals in
 their respective communities. It is at the local community level where these gaps in
 knowledge continue to occur.
- Develop standardized legal literacy materials targeting the different key and vulnerable populations that need them. There should be standard educational tools, such as those developed by SWEAT for sex workers, for LGBT, PWID, or migrants, for example.
- Ensure that paralegals and other similar types of individuals working in CSOs, such as NADCAO, have full knowledge and can provide assistance regarding HIV-related legal and human rights. This should include strengthening skills to assist PLHIV and other individuals from key populations to access justice and redress when their rights are infringed.
- Strengthen the civic education outreach programmes of Legal Aid South Africa, and the DOJCD. This is needed to ensure that they reach and provide rights education to the most marginalised, stigmatised and vulnerable populations highlighted in this report.

4.5.6. HIV-related legal services

South Africa has state institutions which have been developed with the purpose of improving access to justice, especially for the poor. In addition, there are a number of long-standing legal advocacy CSOs which provide both individual legal services and strategic litigation, many of which have their origins in the struggle against apartheid. However, these resources were still deemed by key informants for this component of the assessment as being inadequate to meet the need for accessible and speedy justice for the country's citizens, including PLHIV and the other key and vulnerable populations that are the focus of this analysis. Some of these entities provide interventions that are specific to HIV, while others provide general legal services and access to justice, but are equipped to deal with HIV-related cases. Important examples of this work are described below:

As the state-funded legal services body, and with a network of 128 offices throughout South
Africa, Legal Aid South Africa is ideally placed to address human rights barriers related

to access and uptake of, and retention in HIV services. It has also been mandated and trained to address HIV-related stigma and discrimination and has the organisational apparatus to deliver on this mandate (part of the joint project with SANAC, described in **Section 4.5.2**, above).

- **NADCAO**, through its 320 Community Advice Offices in 9 provinces, many in rural and peri-urban areas, provides general paralegal advice and support. Although not a specific focus, NADCAO confirmed that their member organisations do address issues of access to HIV services on a case-by-case basis (KII with NADCAO, November 2017).
- **Section 27**, which evolved out of the AIDS Law Project, retains a strong focus on human rights in relation to HIV and access to health-care services. As an example of this component of its mandate, Section 27 has represented people who have experienced HIV-related stigma in legal actions, such as the *Gary Shane Allpass vs Mooikoof Estates Pty (Ltd)* case of unfair dismissal on the grounds of HIV status (Section 27, 2011).
- Under the **National Sex Worker Programme**, human rights defenders have been trained to provide advice and referrals for legal and human rights violations against sex workers. SWEAT monitors such violations through the paralegals and via its 24-hour helpline. The organisation has also established a legal clinic with a lawyer and paralegals to provide further legal support when needed. Although these human rights defence activities have not been formally evaluated, SWEAT's *Good practice guide to integrated sex worker programming* (2015) documents how cases reported to the helpline were successfully referred and resolved.
- The **StepUP Project** monitors human rights violations against PWID, including those which pertain to barriers to accessing HIV services. Quarterly reports on human rights violations and responses to these are produced (StepUP Project, 2015). However, there has been no tracking regarding whether follow-up activities have addressed or resolved the incidents that have been reported.
- **SHE**, in partnership with the **Legal Resources Centre**, provides legal support services to assist transgender women with gender amendment issues, including changes to vital statistic registries and identity documents, as well as for instances of discrimination in the workplace and elsewhere.
- The Hate Crimes Rapid Response Team provides support (health, psychosocial, legal) to people who have experienced hate crimes, and supports case management by the police and justice sectors. Included in their work is ensuring that people who have been exposed to SGBV have access to PEP.
- The REAct human rights monitoring and response model, developed by International HIV/AIDS Alliance, and modified for use in South Africa, is being coordinated by Positive Vibes, in partnership with other organisations such as GenderDynamix and SWEAT, under the KP REACH regional grant.²¹ The model involves working with local CSOs and

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²¹ The tool is available at: http://www.aidsalliance.org/assets/000/001/310/REAct_User_Guide_original.pdf?1424259862

constituencies to train and support 'REActors' to recognise, document, and plan interventions to address human rights violations in their communities. Although REAct is being implemented in 8 SADC countries under KP REACH, in South Africa, it is only being implemented in the Western Cape. Learnings from implementation of REAct over the past 3 years indicate that, besides the gathering of data, the intervention has had several positive spin offs for key-population-led organisations, including improving the analysis of collected data and it use for advocacy purposes at both local and national levels (KII with Positive Vibes, December 2017).

• The **Equality Courts** provide a mechanism for less formal and accelerated hearing and resolution of cases of unfair discrimination, hate speech, or harassment, amongst other claims. The Courts have been used strategically by the SAHRC and CSOs to address a variety of issues which have included unfair discrimination against a transgender pupil in Limpopo, for example. However, it was generally acknowledged that the Courts are underutilised. The main reason for this was thought to be that awareness of the Courts is low, especially amongst the poor and marginalised communities (including PLHIV and key and vulnerable populations). According to the DOJCD, the reality of inadequate resources does not allow them to promote the work of the Courts at the level of communities where these services are most needed (KII with DOJCD, November 2017).

Some gaps and challenges were identified for this component of the assessment. They included:

- The main gap articulated by assessment participants was the lack of a national framework to consolidate the monitoring of, and response to, HIV-related human rights violations. Data was not gathered, consolidated, audited or analysed nationally in any systematic fashion, neither was it shared between CSOs and government. Instead, 'single issue' reports come out periodically which, although important, do not always galvanise the full range of HIV stakeholders to take collective action.
- For generic human rights organisations, HIV did not appear to be a priority area for intervention against a backdrop of multiple (sometimes competing) human rights and social justice challenges.
- Given the amount of anecdotal evidence from key informants regarding the obstacles to foreign migrants accessing health care, including HIV services, no access to justice projects for migrants dealing with this issue were identified. While organisations such as **Lawyers for Human Rights** have a migrant rights programme and undertake strategic litigation, they did not appear to have undertaken cases relating to HIV.

A more comprehensive approach to the provision of HIV-related legal services and access to justice in South Africa for PLHIV and other key and vulnerable populations should therefore include the following:

• Establish a national mechanism for the consolidation, auditing and analysis of HIV-related human rights violations towards PLHIV and other key and vulnerable populations. SANAC with the SAHRC should take a leadership role in this regard, but must develop the mechanism with full consultation with PLHIV and key population constituencies. The mechanism should include an on-line platform for human

rights monitoring and case management.

- Scale up the REAct model to more provinces to support the national monitoring mechanism. This includes providing sufficient technical and operational capacity to local PLHIV and key-population-led CSOs to undertake community mobilization, reporting and verification activities.
- Extend and subsequently promote the role of Legal Aid South Africa to provide legal support and representation to all people (including key population constituencies, not only PLHIV) who have experienced HIV-related legal or human rights challenges and who qualify for services. This will include strengthening the technical capacity of Legal Aid to respond to human rights challenges faced by key and vulnerable populations. It will also include expanding its community outreach function to ensure that members of key and vulnerable populations in local communities are aware of the services it can provide.
- Provide increased financial and technical support to NADCAO members so that Community Advice Offices and their paralegals can undertake outreach and can reach more PLHIV and other individuals from key and vulnerable populations with their services. This important resource is currently very underutilised by individuals in communities who need such services.
- Provide a cadre of peer educators working with key populations in local communities with training and support to work as human rights defenders/paralegals. These would involve existing peer educators who are already well-connect with key population constituencies and who can assist with information, mediation and dispute resolution, or can refer and accompany individuals to entities like Legal Aid South Africa, Equality Courts or Community Advice Offices. The SWEAT model can be built on for such training.

4.5.7. Monitoring and reforming laws, regulations and policies

The assessment identified the following efforts to monitor and reform laws, regulations and policies:

• TAC has played a critical role in health system accountability monitoring, with a focus on HIV, either as an individual organisation or in partnership with other organisations. As an example of a broader partnership, TAC participates in the Stop Stockouts Project (SSP) dedicated to highlighting the chronic shortages of essential medicines, with a focus on ARVs and TB medicines. .²² This coalition argues that access to rights-based health care is meaningless if the public health system cannot carry out its mandate of delivering basic health services. SSP was initiated by Section 27, and along with TAC, includes Médecins sans frontières, the Wits Rural Health Advocacy Project, Rural Health Doctors Association of Southern Africa, and the Southern African HIV Clinicians Society.

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²² See: http://stockouts.org/

- The **SAHRC** continues to address HIV-related discrimination as well as discrimination and violence against LGBT constituencies.²³ In a recent report on the state of civil and political rights in South Africa, the SAHRC addressed the issue of hate crimes and hate speech against LGBTI constituencies in the country (SAHRC, 2017). Reporting by the SAHRC on HIV or key population-related cases it is dealing with is not current, however.
- The campaign for decriminalisation of sex work has been in existence for two decades, and has been increasingly scaled up and broadened, especially around the release of the SALRC report on decriminalisation (SALRC, 2017). The work of the **Asijiki Coalition** in this regard has been mentioned previously in this report. Due in a large part to this advocacy, in 2017, the ANC National Conference resolved to fully decriminalise sex work.²⁴ However, decriminalisation is by no means a *fait accompli* as yet for the country.
- Additionally, Women's Legal Centre has engaged in strategic litigation in support of the constitutional rights of sex workers. For example, a recent legal action was resolved in favour of a sex worker who had approached the Commission for Conciliation, Mediation and Arbitration for support following her alleged unfair dismissal from a brothel (NSWP, 2017). The case set a legal precedent for the protection of sex workers' labour rights in the country.
- Advocacy for the reform of drug-related laws is in its infancy. Advocacy for the reform of laws relating to marijuana use, and some successful strategic litigation, has occurred but wider issues of drug use have not yet been taken up.²⁵ Although advocacy around decriminalisation of marijuana is not linked to HIV, it was viewed by key informants in this study as the 'thin end of the wedge' in creating more tolerance and in decreasing hostility towards drug users. The PWID constituency is continuing to emerge in the country with a growing visibility of advocates for the rights of injecting drug users in the context of HIV and more broadly.
- The TB/HIV Care Association hosts a **Drug Policy Week** which is attended by many of the leading drug policy role-players in South Africa. During the week, local and international drug policy experts discuss drug policy reform, including harm reduction.²⁶ Furthermore, **SANAC** and the **CDA** have recently pledged to collaborate more closely to ensure that HIV considerations within the new NDMP are strengthened.
- CSOs working in the gender sector have long advocated for a National Strategic Plan to address GBV, arguing that GBV is a national crisis and needs a nationally coordinated and adequately resourced response to match the HIV response. Furthermore, activists point to GBV as a leading driver of HIV. Lobbying is directed at the Department of Women in the Presidency, which has been criticised for a lack of strategic leadership in responding to the unacceptably high levels of GBV. In the interim, CSO's have developed a Shadow

²³ See, for example, https://www.sahrc.org.za/index.php/sahrc-media/news/item/474-sahrc-intensify-advo-cacy-for-the-lgbti-human-rights

²⁴ See, for example: http://ewn.co.za/2017/12/21/anc-s-decision-to-fully-decriminalise-sex-work-welcomed ²⁵ In 2017, the Western Cape High Court ruled that it was a Constitutional infringement to prevent the private use of marijuana. A case is now before the Constitutional Court on this issue. See, for example: https://www.news24.com/SouthAfrica/News/concourt-set-to-hear-dagga-couple-case-20171107

²⁶ See: http://www.sadrugpolicyweek.com

NSP for GBV.²⁷ The relationship between the Department and CSOs has become adversarial and was perceived to have reached a stalemate at the time the assessment was conducted.

Across these efforts, there are some important gaps and challenges:

- The PWID sector faces many challenges, both internal and external. The internal challenges include the newness of the PWID self-organising model in South Africa, the extreme marginalisation of PWID, and the limited reach of organisations which support them. The external challenges include entrenched negative attitudes towards drug users, the prevalence of the abstinence model and the lack of awareness of and support for the harm reduction approach, as well as weak coordination and commitment from government departments. This significantly limits the effectiveness of current efforts to achieve drug-related law and policy reforms, both in the context of HIV and more broadly. However, the success of the StepUP Project, in terms of number of PWID reached, referred to, and retained in treatment, indicates that the harm reduction approach has succeeded where other approaches have previously failed.
- The capacity of key populations to participate in high-level policy-related discussions and decision-making is growing, but still limited, and this puts excessive pressure on those who have the skills and confidence to participate at that level.
- The Human Rights Accountability Scorecard, as outlined in the NSP, has not been developed.

A more comprehensive approach to monitoring and improving the law and policy environment for removing human rights barriers to HIV services should include the following:

- **Develop and implement a national HIV and TB Human Rights Accountability Scorecard**. SANAC and the SAHRC should collaborate to lead this effort with the full buy-in of civil society constituencies. Sufficient technical and operational support should be provided to fast-track this initiative.
- Sustain the collective effort to revise the provisions in Sexual Offences Act regarding sex work. This should include promoting consultation between government, primarily the DOJCD, civil society and sex worker representatives. The consultations must take full account of the most robust and recent evidence regarding, for example, the significant reduction in the HIV-related vulnerabilities of sex workers, and the improvements in access, uptake and retention in HIV treatment and other services that come about as a result of decriminalization.
- Promote consultation and collaboration between government and civil society to advance drug-related laws and policies which are evidence-based and reduce harms against drug users, including harms related to HIV. This work should include sustaining the Drug Policy Week initiative as an important opportunity for such consultation and collaboration to occur.

²⁷ It is available at: http://genderjustice.org.za/publication/national-strategic-plan-gender-based-violence-shadow-framework/

- Provide sufficient technical and operational support to the CDA so that it fulfills its mandate of coordinating drug use response efforts in South Africa. The strengthening of technical capacity should have as a priority topics and actions related to advance harm reduction.
- Increase the technical and operational capacity of more key-population-led networks and organisations to participate in policy-making processes and to be more effective at lobbying and advocacy. The sex worker networks are the most developed in this regard. Work is needed with more LGBT groups and with PWID constituencies to also be more prominent, active and well-coordinated in national law and policymaking processes.
- Complete the development of the NSP for GBV. Sufficient technical and operational support should be provided to the Department of Women in the Office of the Presidency to lead this effort. Civil society actors should find ways to bring about a *rapprochement* with the Department as this work proceeds.
- Sustain support for strategic litigation. This has become an effective tool for securing the accountability of 'duty bearers', whether in the public or private sectors, for promoting or protecting HIV-related human rights and for removing barriers to services.

4.5.8. Reducing discrimination against women in the context of HIV

As has been noted in Section 4.4.8. above, South Africa is characterised by both enabling and inhibiting factors with regards to women, girls and gender non-conforming people. On the positive side, the legal and policy context is progressive in terms of gender equality; there is professed political commitment to the empowerment of women and the elimination of gender inequality; and, there is an active, sophisticated and vocal women's sector. However, there are large disparities in the realisation of gender equality and related rights for all women. Particularly amongst poor, rural and young women, harmful, patriarchal gender norms continue to fuel SGBV and stigma related to women's SRH, and continue to drive economic abandonment and poverty for many.

Against this background, there is generally a good understanding and analysis amongst key stakeholders of the impact of harmful gender norms as driving SGBV and other vulnerabilities to HIV. Likewise, there is an understanding that multi-level interventions are required to address the complexity of the problem and create meaningful and sustainable impact. Such multiple efforts are underway in many instances; however, they are still not achieving sustained change in terms of substantive improvement in SRH for many marginalised and vulnerable women, including those groups that are the focus of this component of the assessment.

Some important examples of the component of this work that specifically addresses barriers to access to HIV services groups are described below:

Thuthuzela Care Centres (TCCs) were started in 2000 by the NPA in collaboration
with the DOH, DSD, DOJCD and SAPS. The TCCs are specialised centres, based at hospitals, that offer medical and forensic services, psychosocial counselling, case management

and referrals, and police services in one location. HIV interventions, including HTS and PEP, are part of the core package of services. There are also referral mechanisms for other HIV services, such as on-going HIV treatment, where this is needed. Although in practice it is not the case, in the conceptual model, TCCs offer a 24-hour service 7 days a week and are linked to a Sexual Offences Court.

While TCC have a core staffing level defined for them, a study commissioned by the Foundation for Professional Development (FPD) in 2016 reported that only 28% of the TCCs had a SAPS officer stationed on site, and only 46% had a Case Manager (FPD, 2016). Nevertheless, evidence to-date suggests that TCCs have improved the process of reporting and prosecuting crimes of sexual violence by increasing coordination and cooperation across the medical and legal sectors. There are 55 TCCs country-wide, the majority of which are situated in communities with relatively high incidence of rape and sexual assault. Given that there are 413 secondary and tertiary hospitals in South Africa, TCC's only cover 13% of these, and thus most survivors have to contend with fragmented care offered between police stations, the hospital and CSOs.

Three national programmes aim to address the disproportionately high burden of HIV amongst adolescent girls and young women in South Africa. These three programmes are primarily designed to prevent HIV infection, through a combination of biomedical, behavioural, social and structural interventions. Addressing barriers to access to, uptake of and retention in HIV services, is therefore not always an explicit focus, neither is it articulated in the theories of change of these programmes. However, programmes which address harmful social and cultural norms around gender and sexuality, which these programmes seem to do, can also be expected to impact positively on the HIV prevention, treatment and care cascade for young people. These programmes are described below:

She Conquers, the flagship programme of the South African government, is coordinated by the DOH. It is primarily a combination HIV intervention programme, which has as its objectives reducing new HIV infections amongst AGYW, reducing teenage pregnancies, reducing SGBV, keeping girls in school, and improving their economic opportunities. The implementation strategy involves a coordinated approach with other government departments, CSOs and donor agencies. However, according to key informants, is inadequately funded to attain the same scale and reach of this other related initiatives.

The Global Fund programme in South Africa supports six grantees to implement combination prevention interventions aimed at reducing HIV incidence amongst adolescent girls and young women and also to ensure that they access and remain in the continuum of HIV interventions. The implementing organisations are NACOSA; Soul City Institute; Khet'Impilo; AIDS Foundation of South Africa; KZN Treasury; and Western Cape DOH. The interventions are being implemented in ten priority districts by subgrantees. The interventions consist of a package of five services targeted at in and out-of-school females aged 10-24 years, as well as boys aged 10-14 years. The services are peer support; HIV, STI and TB screening and condom distribution; comprehensive sexuality education (CSE); parenting training; and, training of school governing bodies. The interventions aim to shift social norms and increase access to services and commodities to prevent pregnancy, HIV and other STIs. There has not yet been a formal evaluation of this approach and some key informants themselves were undecided on the level of overall effectiveness it was achieving.

• **Determined, Resilient, Empowered, AIDS-free, Mentored, and Safe (DREAMS)** is being implemented in South Africa in five high priority districts through various PEPFAR sub-grantees. These organisations collectively deliver a combination package of evidence-based approaches. Beyond providing and facilitating access to HIV and SRH services, the programme also addresses structural drivers of HIV, including SGBV, teenage pregnancy, dropping out of school, gender inequality, and poverty. The DREAMS programme also has a peer support component whose purpose is to build resilience and social cohesion. Formal evaluations are underway but no results were available to be included in this assessment.

Other efforts to encourage adolescents and young people to use health services, including HIV services, include the following:

- Adolescent and youth friendly health services (AYFHS) are those health facilities that have been accredited by the DOH to provide a set of interventions delivered in a specified manner to serve the interests of adolescents and youth (10-24 years). The objectives of AYFHS are to increase access to and utilisation of SRH and other services; to improve optimal health status; to build capacity of HCWs; to improve service performance for the delivery of services; and to promote services for HIV-infected and exposed adolescents and youth for effective prevention, management, care and support. Accredited facilities must meet a set of minimum standards which require, amongst other things, having policies and process that support the SRH and other rights of adolescents and young people; ensure access to age-appropriate SRH information; and, guarantee privacy and confidentiality. There have been challenges, however, to support AYFHS with sufficient technical and operational resources to sustain them and, currently, they are not available country-wide.
- Process Oriented Approach (POA), developed by Save the Children is a methodology used to deliver CSE with links to SRH services. It addresses socio-cultural barriers faced by children and youth in attaining positive SRHR outcomes.²⁸ It adopts a rights-based approach and takes caregivers on a journey to explore their attitudes to adolescent SRHR and to interrogate what has shaped these attitudes. Using a change management approach, the methodology empowers participants to deal with their own prejudices and helps them overcome personal bottlenecks that pose barriers to their embracing adolescent SRHR. Self-reported data from participants on their experience of the programme has suggested that there were positive changes in mind-set, positive changes in attitudes and behaviour, increased knowledge, and positive impact on personal life and inner self, in addition to other benefits.
- Thohoyandou Empowerment Programme (TVEP) supports three important interventions as described below. Through these projects TVEP provides support, prevention, and empowerment services in the five thematic areas in which they work: HIV/AIDS; child abuse; domestic violence; sexual assault; and support for LGBTI and other vulnerable minorities.
 - **Zero Tolerance Village Alliance** is an alliance of villages in the Vhembe District that take community-based ownership of the social ills that beset their communities,

57

 $^{^{28}}$ See: https://resourcecentre.savethechildren.net/library/process-oriented-approach-poa-sexual-reproductive-health-and-rights

specifically relating to SGBV, child abuse and HIV-related stigma. Villages that want to join the alliance have to meet a list of criteria, one of which is that a minimum of 1,200 men and women must participate in TVEP's four-day rights-based workshop. Outside of TVEP, however, there has been no formal assessment of the degree to which villages are able to make and sustain improvements.

- Zero Tolerance School Alliance (ZTSA), which is an adaptation of the Zero Tolerance Village Alliance and follows the same principles and methodology but is aimed at addressing issues of SGBV and general safety in schools.
- · Victim Advocacy Model is a client-centred programme that ensures individualised on-going practical, emotional and para-legal support for people who have experienced SGBV. The support is offered to women and girls by a female Victim Advocate
 who supports the survivor to adhere to PEP (whenever it is prescribed) amongst other
 aspects of her recovery. The advocate is supervised off-site by Legal Officers who form
 part of TVEP's Access to Justice Team. Anecdotal evidence from programme staff
 suggests that the Victim Advocacy Model has been successful in reducing delays in
 getting survivors to trauma centres and ensuring that doctors examine clients within
 30 minutes of their arrival. Advocacy by TVEP has also resulted in an improved application of investigation techniques by the police, leading to improved case outcomes.

There are also efforts to respond to and prevent gender-based physical and sexual violence for key populations. The work of **SWEAT**, **Sisonke**, **SHE**, **OUT LGBT Well-Being**, **and ANOVA** in this regard has already been profiled in earlier sections. However, a number of key informants were of the view that for many LGBT individuals living in local communities, these efforts did not reach them. It was also stated that many peer educators working in communities were not well trained or equipped to assist individuals dealing with both the physical and psychological trauma of violence and the many barriers in the way of seeking health care and police support in areas were conservative gender norms and homophobia were still strong.

Across all of these efforts, however, some gaps and challenges were identified by key informants. These include:

- A wide range of CSOs agreed that government stakeholders could strengthen their engagement and improve both collaboration and coordination regarding country-wide efforts to address gender in the context of HIV and the broader SRHR needs of women and girls.
- While the TCC model was viewed as an important government-led intervention, there was thought to be inadequate geographical coverage and a lack of funds to remain open over a 24-hour period, including over weekends when most cases of GBV occur. In addition, coordination between the different government entities and civil society partners involved was challenging. Whilst civil society partners in the TCC model play a critical role in addressing the mental health consequences of rape trauma, and as such, contribute significantly to successful justice and health outcomes their function is under-recognised and under-resourced (NACOSA, 2015).

- Concern was expressed about the sustainability of funding for combination HIV programmes for adolescent girls and young women, particularly should levels of external support change. The lack of funding for the She Conquers programme was given as an example of what could result from inadequate funding.
- Many key informants felt that, even though the epidemiological rationale for focussing on priority districts was clear, programmes were ultimately needed in every district.
- In general, it was felt that there should be greater coordination and collaboration between organisations working with adolescent girls and young women and those working with or led by key populations so that the capacity of programmes for adolescent girls and young women to meet the needs of adolescents from key populations could be strengthened and approaches harmonised. One example of the need for such collaboration was with regard to reaching older adolescents below the age of 18 years who engage in frequent transactional sex and/or who sell sex.
- Finally, comprehensive responses to gender-based physical and sexual violence for key populations, particularly those living outside urban areas, are not yet being implemented at sufficient scale to address the on-going urgent need for such interventions. All opportunities to provide such support, through existing peer education programmes, for example, are not yet being fully utilised.

A more comprehensive approach to addressing HIV-related discrimination against adolescent girls and young women, and for addressing other gender-related barriers to HIV services, should include the following:

- **Strengthen and sustain the TCCs.** This should be done on the basis of a comprehensive review and the development of a multi-year plan that incorporates lessons learnt and that emphasises efficiency and sustainability. This should review should pay special attention to what local CSOs contribute and how to strengthen and maintain this component of the model.
- Roll-out other community-based, well-coordinated models to support survivors or SGBV and other forms of physical violence that can be implemented in areas where there are no TCCs. Other approaches are needed besides TCCs given the scale of the challenge that remains in South Africa.
- Critically evaluate the components of combination HIV interventions for adolescent girls and young women that address removing barriers to access, uptake and retention across the continuum of HIV interventions (including adherence to PEP, and PMTCT, for example). Based on the results, develop modifications to programme designs to improve this component where required.
- Sustain interventions involving government and civil society partners to remove barriers for adolescents and young people to access and remain in HIV services. This includes the component of AYFHS, working with adolescents and young people themselves to be resilient to stigma and discrimination in health services and to demand more accountability for change, and, working with communities themselves to take ownership of the health and well-being of young people. Specific attention should be

paid to adolescents living with HIV in all their diversity.

- Empower more adolescent girls and young women to be advocates and community mobilisers regarding ending violence and other harmful cultural practices that limit or deny their SRHR. CSOs in communities should coordinate this work and ensure that effective mechanisms are in place for the safety and protection of these individuals.
- Support SANAC to be more engaged and show strong leadership amongst governmental and non-governmental stakeholders and donors working to address the spectrum of HIV issues for adolescent girls and young women, including barriers to access to services.
- Provide additional training and support to a cadre of peer educators to be able to recognise and respond to individuals and local communities who are victims of gender-based violence but are reluctant to seek support. This should include equipping the CSOs implemented peer outreach programme to provide effective referrals and to accompany clients as well as to continue to support peer educators themselves to address their own psychosocial needs.
- Sustain and scale-up interventions that provide comprehensive support to individuals from key populations that experience gender-based violence in all its forms. SWEAT, Sisonke and other have developed effective models that should be expanded to all key population groups, for example.
- Ensure that programme training HCWs workers on the health needs of key populations include sufficient content on providing medical and psychological support to individuals who have experienced gender-based violence. While this may already be part of the ANOVA model, for example, it was not clear from the assessment whether it was being comprehensively addressed through the I-TECH and DOH programme.

4.6.Opportunities for scaling-up interventions

The preceding sections have outlined what is feasible in South Africa, in terms of the considerable organisational and technical resources which exist within the national HIV response, to reduce or remove human rights barriers to HIV services. The NSP, with its cross-cutting approach to human rights concerns, can serve as the 'blue print' for these efforts. However, for these commitments to move from concept to action, some particular challenges need to be addressed in terms of leader, accountability and coordination:

- SANAC should provide an effective leadership and coordination mechanism for the implementation of the comprehensive response. In this regard, the role of the Law and Human Rights Sector Working Group should be reviewed to determine whether or not in its current form it can fulfil the leadership and coordination role on behalf of SANAC.
- Similarly, key population constituencies should develop a national mechanism for leadership and coordination of work to address human rights barriers. While there are many strong individual entities their work is not yet effectively coordinated. Implemented the

comprehensive response will require that this gap be addressed. As coordinated constituencies they will have a strong and more effective present within the SANAC-led coordination structure described above.

- SANAC and civil society constituencies need to engage government stakeholders more effectively given how most HIV and TB services are delivered through the public sector. This could be done through the SANAC-led coordination structure.
- How funding programmes are structure and delivered, including for Global Fund, should be critically reviewed to ensure that work in communities to address human rights barriers is adequately resourced and that the number of intermediary organisations is reduced. SANAC should consider, for example, supporting specific organisations with high technical competency and constituency credibility to manage and deliver funding for human rights interventions.
- Finally, across the comprehensive response, a stronger emphasis should be place on evaluation, learning and continuous improvement for the design and delivery of interventions to remove barriers.

5. FINDINGS FOR TB

Preventing and treating TB remain critical health priorities for South Africa as it has one of the highest TB burdens globally and one of the highest rates of TB/HIV co-infection. While TB services are delivered country-wide, for certain populations, particularly prisoners, some mineworkers, farm-workers and migrants, significant challenges remain. Access to TB services continues to be inhibited by community-level stigma and misunderstandings about the disease; stigmatising attitudes and practices against certain groups, particularly PWID, on the part of HCWs; complex structural and organisational challenges within prisons; gaps in systems and accountabilities for workplace health and safety measures to reduce TB risk and limited access to justice and redress for those who contract TB as a result; and, challenges to provide TB services in rural and remote areas, particularly for farm workers. While there are a number of efforts underway to address and resolve these challenges, progress is slow, particularly with regard to prisons. There are, nevertheless, opportunities to improve these efforts through more comprehensive and longer-term strategies to address and remove barriers. The sections that follow provide more detail on these issues.

5.1. Burden of TB amongst key and vulnerable populations

In 2015, the latest year for which comprehensive data are available, it was estimated that there were 450,000 new TB infections across South Africa (Massyn et al., 2016). This amounted to a TB incidence of 520 new cases per 100,000 population, with significant geographical variations ranging from 301 in Limpopo to 681 in Western Cape, 685 in KZN, and 692 in Eastern Cape. TB remains the leading recorded cause of death in the country even though the number of deaths has been decreasing year-over-year (ibid). In 2015, there were a 37,878 TB-related deaths accounting for 8.4% of total deaths from all causes (ibid). At the same time, there were 12,693 registered cases of drug-resistant TB (DR-TB), with the highest numbers occurring in KZN, Eastern Cape and Western Cape provinces (Lebina, 2016). South Africa is rated amongst the top ten DR-TB-burden countries globally (Stop TB Partnership, 2017b).

TB/HIV co-infection rates are also very high for the country. Of all new TB cases in 2015, 63% occurred amongst PLHIV (Massyn et al., 2016). HIV screening of TB patients exceeded 95% in most parts of the country, and 56.7% of those screened were HIV-positive. This proportion varies from a low of 38.5% in Western Cape to highs of 68.1% and 68.4% in Gauteng and KZN, respectively (ibid). With regard to the TB burden on the different key and vulnerable population groups included in this assessment, there are, for the most part, no comprehensive or current data. At the time the assessment was being conducted, a national TB prevalence survey was underway to address this gap. The information that was available at the time the assessment was done is summarised below.

Prisoners: One study has estimated that, in 2015, the TB prevalence rate was 2.3% in the country's prisons, a finding that was based on data from only four facilities (Zishiri et al., 2015). More recent data reported by the DCS for 2015/2016 suggested a prevalence rate of 0.9% and also indicated that 83.4 % of those diagnosed with TB had been cured (Makou et al., 2017). What is evident, however, is that the true incidence and prevalence of TB across the prison system remains unknown. Drivers of the TB epidemic in prisons, which have been documented in South African and in regional studies, are severe overcrowding, the lengthy time periods individuals awaiting trial or sentencing are kept in prisons, and the frequent migration of large numbers of individuals in and out of and between prisons (Beyrer et al., 2016; Johnstone-Robertson et al., 2015; Telisinghe et al., 2016).

Johnstone-Robertson et al. (2015) demonstrated the effect of these challenges in their modelling exercise of the probability of TB being transmitted to an awaiting trial prisoner at the Pollsmoor prison in Western Cape. They described the relevant parameters:

"There is a rapid turnover of awaiting-trial prisoners with 79% being incarcerated for periods of less than 12 months. The number of individuals passing through the prison system annually therefore exceeds 368 000. Detainees either awaiting sentencing or awaiting trial comprise approximately a third of prisoners; they suffer the worst prison conditions, frequently being kept in large crowded communal cells housing 40 – 60 inmates for 23 hours per day."

They further argued that implementing international standards could reduce TB transmission, such as improving ventilation in cells, proactive case finding (to reduce delays in treatment), and adhering to national standards for the minimum number of cell occupants (ibid). The extent to which DCS is addressing such recommendations is discussed in **Section 5.4.2**, below.

Mineworkers: Data from the Department of Mineral Resources shows that, of 422,670 miners screened for TB in 2015, 3,773 cases of pulmonary TB were diagnosed (Chamber of Mines of South Africa, 2017). This reflected an incident rate of 884 per 100,000 population, significantly higher than the national rate noted above. However, this calculation was based on program data and cannot be taken a statistically significant estimate. Other studies have estimated much higher rates at 2 500–3 000 per 100 000 individuals (Lebina, 2016; World Bank, 2017). If this is indeed the case for mineworkers in South Africa, it is 10 times higher than the WHO threshold for a health emergency. Mineworkers are at increased risk for acquiring active TB due, among other factors, to silicosis (Chamber of Mines of South Africa, 2017).

The TB burden within prisons and for mineworker is very substantial in South Africa. No other data were available for other groups. The extent of TB disease in the country also indicates the extent of need for TB interventions. Current trends in access and uptake of these interventions is discussed below.

5.2. Trends in service uptake for TB and TB/HIV services

Coverage of TB treatment is improving in South Africa. In 2015, the national treatment success rate stood at 77%, including for newly diagnosed, smear-positive pulmonary TB cases (Massyn et al., 2016). In the same year, 85% of co-infected TB patients were on ART, a significant improvement from 28% in 2011 (ibid). Also in 2015, 64% of diagnosed DR-TB cases were receiving second-line treatment; and, 48% of MDR-TB patients and 24% of XDR-TB patients who started treatment in 2013 were treated successfully although, as is evident, mortality rates remained high amongst this group (Scheibe et al., 2016b).

Available data on access and uptake of TB services for the key populations included in the assessment is summarised below:

Prisoners: Programme data reported by the DCS indicates a trend of improvement in TB screening, treatment and management in the country's prisons. However, with HIV services,

the DCS itself acknowledges, much of this progress is a result of contributions from external partners, which include:

- Right to Care which reported that, in March 2017, TB screening of prisoners on admission had increased by 90% since 2014 in the 80 facilities that it supports (Right to Care, 2017).
- TB/HIV Care Association reported that, in 2015, of the 324,170 prisoners screened for TB, either on admission or during biannual screening campaigns, 1,694 prisoners were subsequently diagnosed with TB and initiated on treatment (TB/HIV Care Association, 2016).

How these data compute to an overall level of access and coverage for TB services could not be determined.

Mineworkers: Data from 2014 show that, of the 4,461 miners diagnosed with TB in that year, 90% were started on TB treatment and that all TB/HIV co-infected miners were started on ART (Lebina, 2016).

No other data on access and uptake of TB treatment for other groups were available. Nevertheless, as least for inmates and mineworkers, there is an upward trend of expansion and improvement but one whose further progress is limited by the human rights barriers identified through the assessment. Before describing these, the law and policy context surrounding efforts to address these barriers is briefly laid out.

5.3. Overview of law and policy context for TB-related human rights

The general law and policy provisions regarding human rights in the context of HIV, discussed under **Section 4.3.1**, above, as they relate to health and access to health services, also apply in the context of TB. In addition, given the level of co-infection, enabling laws and policies for HIV will also address barriers to TB services. There are, just the same, certain laws and policies that have a more direct relevance to TB which are discussed below.

5.3.1. TB-related laws, policies and commitments

In June 2017, the *Regulations Relating to Communicable Diseases and the Notification of Notifiable Medical Conditions* came into effect under the authority of the *National Health Act, 2003* (DOH, 2016). TB, including MDR-TB, are listed as Schedule 2 notifiable conditions, meaning that full nominal reporting is required to provincial and national public health authorities. As a Schedule 2 notifiable condition, individuals infected with TB are subject to provisions that, in exceptional circumstances, allow for mandatory medical examinations and treatment or confinement in a medical facility. Court orders are required for mandatory measures. The regulations stipulate that the country's Constitutional provisions require that such measures are permissible only as a last resort. As these regulations have only recently been gazetted, it remains to be seen how they will be implemented and what effect they will have on reducing the country's TB disease burden.

There are other laws and policies that apply in the context of TB but are not necessarily specific to the management of the disease. These include:

• Occupational Health and Safety Act, 1993, which provides for the health and safety of

persons at work and the protection of employees against hazards through provision of a safe working environment by the employer. Although there are no specific provisions for TB, the legal framework addresses TB-related challenges.

- Compensation for Occupational Injuries Diseases, 1993, and the Hazardous Biological Agent Regulations, 2001, which together provide for the compensation for disability caused by injuries sustained and diseases acquired in the workplace (including TB) by employees during their employment. This excludes the mines, which are provided for in separate legislation described below.
- Occupational Diseases in Mines and Works Amendment Act, 1993, which provides for compensation for TB-related injuries within the mining sector and which is regulated by the DOH. Miners who suffer from TB as a result of risks at work can be compensated when they lose earnings and when there is impaired lung function. The gold-mining sector's collective bargaining agreement from 2007 further provides for additional, paid sick leave (up to 6 months) for employees undergoing treatment for TB (Chamber of Mines of South Africa, 2017).
- Basic Conditions of Employment Act, 1997, which provides for the minimum conditions
 of employment that employers must comply within their workplaces. In addition, provisions within the National Health Act, 2003, address safe working conditions for health
 care providers, including for personal protective equipment as well as safe work spaces.

At the regional level, South Africa participates in the Southern African Development Community's (SADC) *Declaration on Tuberculosis in the Mining Sector* and the *Code of Conduct on Tuberculosis in the Mining Sector* (SADC, 2012a,b). While not having the status of law or regulations in the country, these two instruments reflect a high-level political commitment to addressing TB in the mining sector through, amongst other things, protecting and promoting the rights of mine workers to safe working environments and to accessible and appropriate TB programmes and services.

Finally, it should be noted that, in addition to laws and regulations, there are also guidelines regarding TB management that, amongst other things, translate such provisions into operational procedures. For example, the DOH has issued *National Infection Prevention and Control Guidelines for TB, MDR-TB and XDR-TB* (DOH, 2015). The guidelines address protection of HCW and patients within health facilities from TB exposure. They also address isolation and stipulate that this should be done as a voluntary measure unless specific, exceptional circumstances apply (which have now been clarified in the 2017 regulations).

5.3.2. National strategic plans

The 2017-2022 NSP, which, as already noted, is a consolidated plan for HIV, TB and STIs, is the guiding policy document for the national TB response. The components in the plan relating to human rights, gender, and key and vulnerable populations, discussed in **Section 4.3.3**, above, therefore apply in the context of both HIV and TB.

While it is clear that although South Africa has sufficient law and policy tools to promote and ensure a human-rights-based approach to the prevention, diagnosis and management of TB

disease in most settings, these things are only effective to the extent that they are fully implemented or realised. As the assessment found, it is in this domain where barriers for TB services arise. What constitutes such barriers is described in the next section.

5.4. Human rights barriers to TB services

Through the desk review and the key informant interviews, the assessment identified human rights barriers related to stigma and discrimination, particularly self-stigma; problematic attitudes and behaviours on the part of HCW against some groups, as well as challenges for HCWs themselves who become infected with TB; substantial challenges in prisons; some issues resulted to gender; and, finally, challenges arising from the deeply entrenched poverty that affects a large number of the people living with TB, HIV or both across South Africa.

5.4.1. Stigma and discrimination

TB-related stigma continues to constitute a barrier to seeking TB-related services as well as for remaining in TB treatment programmes. This is despite recent research findings regarding relatively high levels of general population knowledge about most aspects of TB disease (Kigozi et al., 2017; Naidoo et al., 2016). This assessment identified three broad categories of ongoing challenges: TB-related self-stigma and external stigma for individuals in communities; stigma amongst and toward incarcerated people; and, stigma that affects HCW.

5.4.1.1. Community-level stigma

The dimensions of community-level TB-related stigma continue to be complex and affect individuals with TB disease on its own as well as those PLHIV who are co-infected. Qualitative research with TB patients conducted over the past decade points to enduring challenges of self-stigma which is related to perceptions and beliefs that TB is associated with "dirt and squalor;" that having the disease means an individual is also HIV-positive; and that, particularly for those with MDR-TB, their condition is a result of their own reckless behaviour (Murray et al., 2013; Skinner and Classens, 2016; Govender, 2017). Key informants also confirmed that TB-related stigma remained a serious challenge and added that individuals with TB avoid or delay seeking care because of fear of lack of confidentiality, particularly in the way that TB services are organised with contact tracing and directly observed therapy, especially during the initial two-week period of treatment when many TB patients must make daily visits to health facilities. Finally, it was said that, within their households, TB patients still give accounts of being stigmatised or excluded out of fears they will infect others, including as a result of erroneous beliefs that sharing dishes or other household items will lead to infection (Kigozi et al., 2017; KIIs with Aurum Institute, CAPRISA, CareWorks, CDC and DENOSA, November-December 2017).

With regard to individuals who are co-infected, the burden of stigma is compounded. For example, the PLHIV Stigma Index survey, which also assessed TB-related stigma for co-infected PLHIV, found that over one-third (36%) of these respondents reported being teased, insulted or sworn at because of their TB status; 41% reported being gossiped about because of their TB status; and, 27% harboured personal feelings of uncleanliness or dirtiness in relation to their TB diagnosis (SANAC, 2015). In-depth qualitative research has explored further the complex experience of dual stigma such that some individuals will hide or deny their HIV-status as it is a social identity that, in their view, is much more undesirable than being known as having TB disease (Daftary 2012; Daftary and Padayatchi, 2012). Such phenomena have

implications for the provision of integrated TB/HIV care when some individuals prefer that one aspect of the co-infection (HIV) remains distinctly hidden (Daftary, 2015). However, to what degree this affects overall uptake of TB and HIV treatment for co-infected individuals is not known.

5.4.1.2. Stigma amongst incarcerated people

Within prisons in South Africa, the human rights barriers to accessing TB services overlap considerably with those limiting access to HIV services. As already described, prison environments are characterized by a structured power dynamic in which access to services (including health services) is controlled by prison officials and gang leaders (KII with SA Partners, November 2017). Prison officials are perceived as lacking both the knowledge and the inclination to assist inmates in accessing both TB and HIV-related health services. With specific reference to TB, it was reported by some key informants that, if an inmate suspects that they have TB or requests TB services, this may be seen as asking for special treatment, which violates the established power dynamics amongst inmates. As such, an individual may decide not request TB or HIV services unless they are significantly ill and such things are absolutely necessary (KIIs with SA Partners and Just Detention, November, 2017).

5.4.1.3. Internalised stigma amongst health care workers

Key informants described how, across the health sector, the common perception is that, "TB is a disease of dirty and poor people (KII with DANOSA, November 2017)." As a result of this association, HCWs will not disclose their TB status to their co-workers, community, or family members even though most HCWs who contract TB do so as a result of workplace exposure and not their living conditions (KIIs with John Hopkins University and USAID, November 2017). Consequently, other HCWs in facilities are unaware of the numbers of their colleagues who acquire TB and, for this reason, do not put improved measures in place to prevent ongoing TB exposure between staff members or between staff and patients. Furthermore, in requiring TB treatment due to an occupational exposure, healthcare workers (aside from the medical doctors) must generally seek care at the facility in which they work. Fears (and actual instances) that confidentiality will not be maintained, or that they will be the object of stigma from their colleagues, mean that some HCWs will avoid timely treatment or will often use (and exhaust) their medical aid resources by seeking treatment at private facilities (KII with DENOSA, November, 2017).

5.4.2. Punitive laws, policies and practices

The assessment identified no punitive, laws, policies or practices that are specific to TB other than issues related to inmates which are discussed below. Issues affecting key populations' access to HIV services, as described in **Section 4.4.4**, above, will apply in the context of TB, particularly where PWID or sex workers held in police cells are denied access to medications or have them confiscated, for example, and these same individuals are on TB treatment. The use of mandatory measures for TB patients in the general population was not raised as a human rights concern by key informants, perhaps because the regulations addressing such things are new.

There are challenges for inmates, however, in the way that some facilities handle individuals with TB from either a public health or a disciplinary perspective, a situation that is also heavily influenced by the physical conditions of many prisons country-wide. For example, some key

informants did describe examples of mandatory confinement, within a separate locked facility, of inmates with TB who refused treatment, (KIIs with SA Partners and Just Detention, November 2017). The extent to which this is a *current* practice across the prison system is unknown. The management of TB in South Africa's prisons, and the human rights concerns this raises, is a more complex and systemic issue. Of primary concern amongst key informants was the inability of DCS to meet the basic needs of detainees in remand centres where individuals awaiting trial or sentencing are held (Johnstone-Robertson et al. 2015; KIIs with Sonke Gender Justice and Right to Care, November 2017).²⁹ Such basic needs include food, sanitation, heat, and personal safety.

Poor infection control in cells, including an unwillingness to open windows, was also described by key informants in the context of TB as inmates are often cold and do not have sufficient blankets (KII with DENOSA, November 2017). Thus, even if they are aware of the consequences of poor ventilation within confined spaces for the spread of TB, they are unlikely to open the windows as their need for a warm environment is more important. Furthermore, requesting for a window to be opened requires the permission of the cell leader or 'general.' These individuals have a substantial amount of power over other inmates, including their access to TB services. As one key informant described, "You cannot tell a 'general' to get screened for TB if he is coughing. If a general is not on board, infection control won't happen, guys won't access services (KII with SA Partners, November 2017)."

One other issue identified by key informants was that inmates in all facilities have the potential for poor adherence to TB treatment as they often receive only two meals per day (often breakfast and lunch), as per DCS policies governing food services, which for some inmates are insufficient to support their TB drug regimens (KIIs with Just Detention, Right to Care and SA Partners, November 2017). As a result, these inmates may default from TB treatment due to side effects resulting from poor nutrition. In addition, whereas special food allowances were previously provided to TB patients, this policy within DCS has changed and the provision of extra food is now based on a low body mass index as opposed to a TB diagnosis on its own. Key informants noted that, previously, some inmates were motivated to undergo TB screening and diagnosis for the potential to gain extra food rations if diagnosed with TB; however, this is no longer the case (KIIs with Just Detention, Right to Care and SA Partners, November 2017). These same informants described how, in some exceptional cases, detainees with TB will delay or interrupt treatment to achieve a low body mass in order to be eligible for the additional food.

These problematic aspects regarding TB prevention and management in prisons in South Africa are one component of a much larger challenge that was beyond the scope of this assessment to address. It was clear from key informants, however, that unless issues of overcrowding, adequate nutrition and the physical state of prison facilities are addressed, a number of the challenges that directly affect TB cannot, on their own, be resolved.

5.4.3. Barriers related to gender

The gendered dimensions of the TB epidemic in South Africa are continuing to be explored. This includes how aspects of gender affect uptake and retention in TB services. There are some

²⁹ This issues were also highlighted in the media during World AIDS Day coverage. See, for example: https://www.pressreader.com/south-africa/the-star-late-edition/20171201/281805694252736

important differences for men and women in this regard (Govender, 2017; Skinner and Classens, 2016). For men, for example, there can be delays going to health facilities for diagnosis or treatment due to fears around income loss for their households (see below) as well as to avoid a perception that they are somehow weak as men for falling ill in the first place (ibid). TB patients are largely cared for by nurses who are overwhelmingly women and for some men they are uncomfortable in these environments. Furthermore, the majority of health system users are also women and, as one male TB patient in Govender (2017) stated:

"It doesn't make me feel good. Because now everyone is looking at me. You come and the majority are just women. "What is this man doing here? What is he here for? He is here every day?" But they also know what you are coming for."

For women, barriers to TB diagnosis and care relate to their social role as home-makers and care-givers (Govender, 2017; Skinner and Classens, 2016). Sickness means that they are compromised in these roles but must still carry them out regardless. For the poorest households in South Africa, there is a daily struggle to find money and food (see below), something that many women are responsible for. Being sick with TB and not able to do this 'work' during the initial phases of TB treatment can be catastrophic and plunge these women into greater depths of vulnerability, including violence and abuse (Govender, 2017). Children will also suffer in these circumstances.

5.4.4. Barriers related to poverty

Some recent studies have mapped the socio-economic dimensions of uptake and retention in TB programmes. For example, Foster et al. (2015) collected data from a group of 618 individuals living with TB in public health clinics across four provinces. Only 25% of the group had formal employment and 35% had no income at all. Another 12% was relying on social grants. The study found that, for the poorest participants, the additional costs of TB disease, in terms of transport cost to health facilities, income loss, and costs for caregiving, could be catastrophic and lead towards a "medical poverty trap." Of those who were otherwise eligible for disability grants, only 5% accessed them over the six-month course of treatment. In another effort, Govender (2017) found that, amongst male TB patients in Cape Town, the prospect of having no income (most had no formal employment but some earned income through 'piece work') and not being able to support their households was a major factor in deciding whether or not to seek treatment.

Key informants confirmed these findings, highlighting the economic hardship on households which even before a member was diagnosed with TB were challenged to find enough income for food or shelter. They stressed how, in their view, this was the situation of a majority of TB patients (KII with DANOSA, November 2017). Others spoke more specifically about mineworkers and their families whereby, particularly for men who are contract workers, workplace services do not always extend to family members nor is there always protection from income loss during TB treatment (KII with TEBA, November 2017). It is the women and children in these households that are most affected by these gaps as the burden falls on them for caregiving and for finding ways to support household needs, even while they themselves may also develop TB disease (see above). The level of impoverishment and the deplorable environmental conditions of communities surrounding many of the country's mines has been a subject of national concern although with little concerted action on the part of government or mine owners to improve things.³⁰

2

³⁰ See, for example: https://pmg.org.za/committee-meeting/14901/

5.4.5. Harmful working conditions and exploitation

The assessment identified areas where individuals and groups are placed at elevated risk for TB exposure and experience barriers to TB services as result of working conditions. These issues primarily involve farm workers, mineworkers and HCWs.

According to key informants working with farm workers, these individuals often have limited access to workplace health services except during annual health screening campaigns which may or may not include TB screening (KIIs with AgriAid SA, TEBA and WHO, November 2017). Those who fall ill outside of these times frequently go undiagnosed. Contract workers and seasonal workers within the farming or mining sectors also have limited access to workplace programmes to support their health needs as they lack the benefits accorded to permanent employees (as noted above). It was also said that some farm managers, for example, would opt not to renew seasonal workers' contracts if they had TB, partly in an effort to prevent others from being infected (KII with AgriAid SA and DENOSA, November 2017). As a result, seasonal workers are very reluctant to use TB services and seek treatment only when TB disease is very advanced (KII with TEBA, November 2017). For others, once they believe their condition has improved, they stop TB treatment and return to work, largely as a result of the fact that they have no paid sick-leave benefits (KIIs with TEBA and WHO, November 2017).

With further regard to mineworkers, in addition to what key informants contributed to the assessment, Adams et al. (2017) have highlighted mineworkers' distrust of mining companies' health facilities and workplace programmes that encourage them to be aware of TB and to seek treatment. This distrust and avoidance of these interventions frequently arises from workplace stories or rumours about others being effectively 'fired' when they presented for TB diagnosis and treatment. The belief then takes hold, whether it is fact-based or not, that revealing one is sick with TB could result in job loss. Key informants described examples where, if such individuals acquire TB, they can be medically boarded with no benefits and effectively lose their employment (KIIs with TEBA and WHO, November 2017).

The prison conditions described above also expose prison workers to TB infection. In addition, key informants described how poor knowledge about and implementation of basic infection control measures, as well as a lack of infection control supplies such as extractor fans or ultra-violet (UV) lights, or personal protective equipment such as masks, adds to the risk of workplace exposure (KIIs with DENOSA and John Hopkins University, November 2017). These same key informants also noted that when extractor fans and UV lights are present, they are installed only in the treatment rooms and not at reception stations or in waiting areas. Similarly, where HCWs do have access to N-95 masks, they often wear the same mask for prolonged periods of time.

Key informants also described how, although the infection control policy is there to manage the risk of TB exposure in health care settings, the implementation of these measures in work-places is highly inconsistent, and accountability mechanisms are either not clear to those at high risk of exposure or not enforced by those with the responsibility to do so (BheBhe et al., 2014; KII with DENOSA, November 2017). For the health care system in South Africa, however, lack of accountability for workplace conditions for HCWs is a system-wide challenge.

5.5. Efforts to address and remove barriers

5.5.1. Overview

Within the range of barriers this analysis has identified, a number are very specific to the national TB response and directly affect access to TB services. Others are structural and systemic and, although they too affect access to services, they extend far beyond the specific context of TB. With regard to both categories, stakeholders in South Africa are engaged in efforts to reduce or remove barriers to TB services, some of which is being done in the larger context of securing the right to health through, amongst other things, promoting access to safe and reliable health services and through interventions to demand stronger accountability on the part of government to fulfil its health-related Constitutional requirements. Examples of all of these efforts are described below. While a number of them are making substantive progress, some important gaps and challenges remain. In this regard, specific actions to address these issues and to achieve a comprehensive approach to addressing and removing barriers to TB services are set out.

5.5.2. Integrated approaches

Overall, a variety of TB prevention, screening, diagnostic and treatment programs have been implemented country-wide. Some of these efforts contain elements addressing some human rights barriers, such as stigma and discrimination reduction, TB-rights literacy, and advocacy and support for workplace health and safety. While these efforts are immensely important for the national TB response, and particularly for the key populations included in this component of the assessment, it was difficult to isolate the specific human-rights-related strands within these comprehensive approaches and, as a result, to gauge their effectiveness. What is important to note, however, is how programmes that specifically focus on key populations for TB are largely externally funded and heavily relied on by the DOH, DCS and others to address their technical or operational capacity challenges, on the one hand, and, on the other, to fill gaps in their own Constitutionally mandated accountabilities to provide these interventions themselves. Nevertheless, these and other efforts to address human rights barriers to TB services are described below.

5.5.3. Reducing stigma and discrimination

Work to address TB-related stigma and discrimination occurs either as direct interventions are as components within boarder TB and HIV programming. The following examples illustrate this.

The DOH, its provincial counterparts, and its national and international partners have implemented specific TB stigma reduction programmes or have included anti-stigma messages in efforts to raise awareness about TB country-wide, and to encourage individuals to be screened and diagnosed. For example, with funds from PEPFAR, URC has collaborated with the DOH and NGO partners to implement TB-stigma reduction activities that included television and radio advertisements, posters and other IEC materials, and interventions in schools. More recently, the DOH and its partners led country-wide participation for World TB Day in March, 2018, which had as its global theme "Unmask Stigma."³¹

71

³¹See: http://www.unmaskstigma.org

- Through sub-granting, URC, TB/HIV Care Association and Right to Care gave engaged community partners to include TB stigma reduction in their efforts to increase awareness about TB and to mobilise communities to undergo screening.
- Reducing TB-related stigma is also a component of work done by civil society partners with integrated HIV and TB programmes. For example, TB is included in the national stigma reduction campaign being implemented by the **Soul City Institute**, described in **Section 4.5.2**, above. **TAC**, as part of its work in communities, as well as through its national campaigns, also addresses TB stigma reduction.

There are challenges within these efforts, however. Community level attitudes and beliefs stigmatizing TB endure despite all of the work aimed at changing this. Much of this unresolved burden of stigma is self-stigma. More comprehensive, local level efforts are needed to focus on this at the individual and community levels with the dual purpose of changing community attitudes and beliefs about TB, and of building personal and collective resilience to challenge and resist stigma. More focused attention is also needed to assist individuals struggling with dual-stigma.

A comprehensive approach to reduce TB-related stigma and discrimination should include the following:

- Sustain country-wide programmes to raise awareness about TB and to reduce stigma and discrimination. This work should become more 'granular', however, to reach deeper into communities.
- Sustain and expand interventions that mobilise communities to understand and reduce stigma and discrimination. More financial and technical resource are needed at the 'ground level' where stigmatizing attitudes and practices regarding people with TB in communities continue to occur.
- **Develop a multi-year action plan to reduce stigma and discrimination**. The plan will ensure that work by different stakeholders in different sectors to address TB stigma is more consolidated and coordinated. The plan will also provide the mechanism for tracking progress.
- As part of the action plan, put in place a national coordinating mechanism for TB stigma reduction. For stigma and discrimination reduction efforts to have more impact, a national coordinating mechanism is critical.
- Scale-up interventions to address dual stigma. Counselling materials and approaches should be reviewed to ensure that they can assist co-infected individuals with managing self-stigma.
- Scale-up qualitative research on TB and TB/HIV stigma, particularly self-stigma. The enduring nature of community and personal level stigma is still not fully understood in South Africa. Additional qualitative research is needed to ensure that interventions to address stigma are evidence-informed and properly oriented.

As the assessment found, the gender-related aspects of TB affect both women and men. For women, this relates to challenges of poverty and their role as care-givers, particularly in for the poorest TB-affected households. Aside from what is provided through the DOH TB programme in terms of local TB services, the assessment identified no specific intervention focused on issues for women. The findings do suggest, however, that the following actions could be taken to address issues of poverty and vulnerability for women in the context of TB:

- Scale-up up efforts in communities to improve access to social support for TB-affected households, including for disability grants. Many of the poorest, TB-affected households are not yet accessing such support.
- Strengthen advocacy work for mining communities to ensure that mining companies support households of TB-affected miners. The burden of caring for sick miners primarily falls on women in these communities who are not consistently included in workplace programmes that support their spouses or partners.

With regard to issues for men, different stakeholders have called for more options for how HIV and TB services are provided, including making services available outside of working hours and having 'men only' days or evenings. Research by Daftary et al. (2015) has called for a 'revisioning' of TB service provision that allows for more patient autonomy and privacy and that moves away from a "top down approach disease management." The assessment did not identify any stakeholders currently taking up this work but it could provide an opportunity for addressing men's concerns regarding how they access TB services.

5.5.5. Legal literacy

There are some efforts to promote legal literacy in the context of TB. These include:

- TAC, as already described, works to promote health rights literacy in communities and, although not specific to TB, the content will apply to a number of TB-related concerns, such as non-discrimination, privacy and informed consent, and the right to safe and reliable health care services. TAC's work to empower PLHIV to actively participate in district and provincial health governance structures also creates opportunities where issues regarding TB services can be raised within the health rights frame.
- The DOJCD has on its web-site World Economic Form publications on TB and human rights (however, no key informants mentioned this resource so it is not clear how much it is accessed or used).³²
- South African civil society representatives participated in the development of ARASA's activist manual Close the Gap: TB and Human Rights. The guide is meant to empower TB, HIV and health activists to promote and protect human rights in the context of TB.³³

A more comprehensive approach to ensuring that individuals and groups living with or at high risk of TB understand and realise their legal and human rights should include the following:

Sustain and expand community-level activities to promote human rights literacy in the context of TB, particularly for issues of privacy, confidentiality

³² See: http://www.justice.gov.za/vg/hiv/hiv docs tb.html

³³ See: http://arasa.info/files/3914/4922/6648/Activist guide final double spread.pdf

and autonomy. This should include using standard tools and scaling-up community level dissemination of materials.

- Continue to include TB-related human rights components in communitybased rights literacy programmes for HIV. This is essential in the context of South Africa's high rate of HIV/TB co-infection.
- Increase the capacity of community-based entities to promote TB human rights literacy. A number of community-based groups are contracted to assist with community mobilization activities for TB awareness, TB screening, DOTS and contract tracing. All of these groups should have a high level of competence to also promote TB human rights literacy.

5.5.6. Monitoring and reforming laws and policies

The assessment identified the following examples of activities with the objective of monitoring and improving the law and policy environment for TB programmes, including strengthening the accountability of government, employers and others for their legal responsibilities to provide services and to protect workers and others from exposure to TB:

- TAC and Section 27 routinely address TB-related issues. Recent work includes participating in the finalising of the public health regulations on notifiable conditions (discussed above), and monitoring the implementation of TB components of the NSP, including TB in prisons and treatment for MDR-TB.³⁴
- TAC has also used its provincial chapters to monitor infection control standards in health facilities and to use the information for advocacy purposes. Results for 207 facilities were released in 2018 just prior to World TB Day and showed major gaps in basic measures such as opening of windows in waiting areas.³⁵
- Mining unions in South Africa, particularly the Association of Mineworkers and Construction Union and the National Union of Mineworkers, are active in promoting and securing workers' rights, including strong health and safety laws and regulations as well as full accountability on the part of mining companies to guarantee these things for their employees. TB concerns are included within the broader reach of these efforts.
- South Africa participated in the regional, 10-country TB in the Mines in Southern Africa (TIMS) initiative funded under the Global Fund from 2016-2017. One component of the project was to improve the law and policy environment across the sector with an emphasis on work place health and safety, labour rights, and social protection. The final evaluation of the project is not yet available. A new phase of activity has been planned but not yet launched.

A more comprehensive approach to monitoring and reforming laws and policies to protect and promote human rights in the context of TB should include:

³⁴ See http://section27.org.za/priority-work-areas/

³⁵ See: https://tac.org.za/news/red-alert-on-tb-infection-control-in-clinics/

- Sustain efforts by civil society to monitor human rights trends in the context of TB. This includes information gathering in communities as well as media and advocacy campaigns.
- Sustain support for strategic litigation. As with issues related to HIV, strategic litigation has become an effective tool for securing the accountability of 'duty bearers', whether in the public or private sectors, for promoting or protecting TB-related human rights.

The assessment identified that, at least for some TB patients, including some men, the organization of TB services erodes their privacy and confidentiality, particularly the aspect of DOTS. Daftary et al. (2015) have also taken this issue up in their research. To explore this issues further, the comprehensive response should:

Support additional participatory action and operational research, and pilot programmes for new approaches to TB care that empower patients and respect their privacy and confidentiality. The current 'top down' disease management approach, with DOTS and contract tracing, deters individuals from seeking diagnosis and treatment, particularly men.

While not a current issue for TB in South Africa, it may become more prominent as new public health regulations are rolled-out. Therefore, a comprehensive approach should include:

 Support civil society to monitor the implementation of the new public health regulations, particularly the aspect of mandatory measures.

5.5.7. TB-related legal services

TB-related legal claims can be pursued through the same mechanisms as those for HIV. There have been some important legal interventions specific to TB concerns, the most well-known being the case of *Lee v Minister of Correctional Services (CCT 20/12)* and the subsequent legal actions the case engendered.³⁶ Dudley Lee contracted TB while he was an awaiting trial inmate at Pollsmoor prison between 1999 and 2004. Lee sued the Minister of Correctional Services for failing to implement the measures required by law to decrease the risk of disease in prisons. After a seven-year court battle, Lee won his case and was awarded damages. The ruling compelled the DCS to take measures to address the overcrowded and unhealthy conditions in prisons (Makou et al., 2017).

Civil society organisations working on law and social justice issues will also support TB-related interventions. These include the **Wits Justice Project** and the **Centre for Applied Legal Studies**, both of which had standing as *amici curiae* in the *Lee* case. The class action intervention of *Bongani Nkala v Harmony Gold Mining Company Limited & Others* is ongoing. The case challenges 32 gold mining companies for failing to protect workers and their families

³⁶ The text of the Constitutional Court judgement is available at: http://www.saflii.org/za/cases/ZACC/2012/30.pdf. However further legal action, brought by Sisonke Gender Justice was necessary to compel the DCS to implement aspects of the guidelines that directly related to the Constitutional Court judgement.

against the impacts of illness and death arising from silicosis and tuberculosis. **Sonke Gender Justice** and **TAC** have standing in the case as amici curiae on the tuberculosis component.³⁷

A more comprehensive approach to improving access to justice for TB-related legal matters should include the following:

Provide training or technical support, where needed, to ensure that legal service providers (mentioned under HIV, above) can address TB-specific legal concerns. Such concerns will include access to compensation and other benefits, unfair employment practices, and discrimination in communities, amongst others.

5.5.8. Sensitising law makers and law enforcement agents

Other than work undertaken in relation to TB in prisons, the assessment identified no TB specific interventions in this programme area. To address this gap, a comprehensive response should include the following:

- Integrate content related to TB in the sensitisation and engagement activities with law enforcement agents and others described under HIV, above.
- Sustain civil society advocacy for proper judicial oversight of prison conditions. As part of this work, ensure that TB specific issues are included of the oversight process.

5.5.9. Training of HCW workers on human rights and medical ethics

A number of partners working with the **DOH** support training of HCWs to provide comprehensive and competent TB services. These include **URC**, **TB/HIV Care Association** and **Right to Care**, among others. Addressing TB-related stigma, and the importance of patient confidentiality and informed consent, are components of the training although how much emphasis they receive in these programmes the assessment could not determine.

To address TB-related stigma amongst HCWs themselves, **TB Proof** was established in 2012 as an advocacy and support network for survivors of TB and MDR-TB.³⁸ The organisation works to remove the silence around the TB-related risks HCWs are exposed to, and to give visibility to their experiences surviving TB diagnosis and treatment. The organisation also undertakes advocacy and awareness raising in health care facilities to promote accountability for safe working conditions.

Finally, **TAC**, as part of its national and provincial level campaigning activities, has drawn public attention to TB-risks faced by HCWs because poor of working conditions and lack of compliance with infection control standards, including stock-outs of personal protective equipment such as masks.³⁹

³⁷ http://genderjustice.org.za/publication/bongani-nkala-v-harmony-gold-mining-company-limited-others/

³⁸ See: http://www.tbproof.org

³⁹ See: https://tac.org.za/news/red-alert-on-tb-infection-control-in-clinics/

A comprehensive approach to ensuring that HCWs are equipped with the required knowledge and skills to provide ethically competent TB services, and that they are protected from TB exposure, should include the following:

- Review training curricula and training processes to ensure that content on TB-related human rights is included and that it receives enough emphasis in training programmes. Should the review identify gaps, the DOH should take the lead to address them.
- Scale up work by civil society to improve accountability and action on the part
 of the DOH at national and provincial levels for safe working conditions for
 HCWs. As a first step, the work of entities like TAC and TB Proof in this regard should be
 sustained.
- Address TB-related stigma amongst HCWs as part of the multi-year action plan described above. Specific, focused efforts are needed, led by the DOH, to ensure that HCWs who acquire TB disease can be promptly diagnosed and treated in safe and confidential environments.

5.5.10. Mobilising and empowering TB patient and community groups

A number of interventions have already been described aimed at community mobilization and support for people living with and affected by TB. This includes HIV/TB integrated efforts such as those by TAC. It also includes what groups such as the **South Africa National TB Association undertake in communities regarding treatment adherence and finding and support patients lost-to-follow-up**. Not all TB patients have access to these structures, according to key informants, and they are a critical component of addressing TB stigma, particularly self-stigma and dual stigma. Therefore, a comprehensive approach to addressing such barriers should include:

Sustain and expand community-level efforts to support and empower people living with TB to challenge and overcome stigma. This should include TB-specific support groups where needed as well as support for people living with or recovered from TB to work as spokespersons and community mobilisers.

5.5.11. Improving access to TB services for people in prisons

With regard to South African prisons, as result of the *Lee* case, in 2013, the DOH issued the *Guidelines for the Management of Tuberculosis, Human Immunodeficiency Virus and Sexually Transmitted Infections in Correctional Facilities* (DOH, 2013). The guidelines contain a section on human rights. This includes issues such as the rights of inmates to receive services in private and confidential settings; to be confined in settings that are hygienic and conducive to health; and not to be isolated from the general prison population because of their HIV or TB status except in circumstances where there is an imminent threat to the health of other prisoners. The guidelines also address the labour-related rights of prison workers to work in safe environments that protect them from exposure to TB and other communicable diseases. However, as this analysis has described, the technical and operational ability of the DCS to fully implement these guidelines in all its facilities remains limited, even with the extensive external support it receives from its partners.

There are, nevertheless, a number of activities underway to improve access to TB services in prisons and to reduce TB-related health risks. In addition to the internal efforts of DCS, these activities include:

- Sonke Gender Justice undertakes a number of activities aimed at securing the rights of prisoners, including to TB and other health services. Its 'One Judge, One Jail' Campaign brings together the judiciary, the Judicial Inspectorate for Correctional Services and civil society to improve judicial oversight of prison conditions, as prescribed in the Correctional Services Act. The organisation also makes regular submissions to the Portfolio Committee on Correctional Services on issues such as sexual abuse, HIV and gender inequality.⁴⁰
- The **DOH** implements a programme to support and educate inmates about their rights. Called "On the Other Side of the Mountain," a component of the programme focuses on the right to health. As part of this component, inmates are given information on how to utilise internal structures if they need or want HIV or TB services.
- Right to Care has a Right to Health programme which educates DCS members and inmates on their health rights.
- The **Detention Oversight Forum** has been established to advocate for improved prison
 conditions, and for greater transparency related to the human rights abuses faced by inmates and other detained persons.

Despite these efforts, the following major gap was identified:

• The work of NGOs is limited in reach. For example, Just Detention currently works in the three major cities only. Although the SA Partners programme has expanded to all six DCS regions, encompassing 243 correctional facilities with a target of reaching 70,000 inmates, the programme has still not been able to reach all facilities. In addition, centres for juveniles and prisons for women are largely unreached by NGO efforts.

A more comprehensive approach to addressing human rights barriers to TB services in prisons and other closed settings should include the following:

- Support NGOs to scale-up sensitization and TB literacy trainings with DCS members and inmates to improve facility-level mobilization, collaboration and support for TB control in prisons. Current efforts in this regard do not cover all facilities.
- Strengthen coordination mechanisms between the DCS and other government departments (such as the DOH and SAPS) and stakeholders (NGOs) to improve the effectiveness and impact of TB interventions within prisons.

⁴⁰ See, for example: http://genderjustice.org.za/publication/submission-to-the-portfolio-committee-on-correctional-services/

- Provide HCWs in prisons with full occupational health support to reduce their risk of TB exposure and to support them with full benefits should they acquire TB disease.
- Scale up programmes led by former prisoners that support newly released peers to transition back to communities. These programmes should include counselling and support for stigma reduction and that ensure linkages to health facilities for TB and HIV care.
- Scale-up parolee and civil society led advocacy for prison reform with a priority on improving basic conditions in prisons for reduction of TB and other
 health risks. The full engagement of former prisoners as advocates and spokespersons
 within current efforts is an important gap that should be addressed.

5.6. Opportunities for scaling-up interventions

As with the national response to HIV, the NSP is also the 'blueprint' for the national TB response and the framework within which to situate the recommended actions for achieving a more comprehensive response to remove human rights barriers to TB services. The NSP structures also provide opportunities for greater collaboration and integration of these efforts across the HIV and TB domains. Such integration is in progress for the country, but more commitment and focus are needed to fully benefit from the improved coordination, effectiveness and leverage across the HIV and TB sectors that this integration could achieve. This would also ensure that the wealth of organisational, intellectual, social and economic capital which exists within the national HIV response it equally engaged to address TB-related priorities.

Some specific issues should be addressed as efforts to strengthen and scale up efforts to remove barriers to TB services proceed:

- The considerable data gaps for current, comprehensive information on the burden of TB for key populations, as well as on trends in access and uptake of TB and TB/HIV services for these groups, should be addressed and closed. Without this data, the extent of current barriers and their impacts cannot be fully comprehended which, in turn, inhibits how interventions to address barriers can be planned, implemented and evaluated.
- A greater technical and financial priority should be placed on supporting community-mobilisation and empowerment activities which are most effective to reduce stigma, especially self-stigma, and to motivate and empower individuals living with or affected by TB to resist such stigma, and to demand that barriers to their access and uptake of services be removed. The focus of such efforts should be on the key populations for TB.
- There should be greater collaboration between CSOs working on TB-related rights and responsibilities with the prison reform movement as such a combined effort will potentially have greater effectiveness in achieving comprehensive change, particularly with respect to the structural and underlying conditions within prisons that fuel the ongoing epidemic of TB in these settings.

SANAC should clarify and strengthen its role as the coordinator of human rights actions
to address barriers to TB services. For many stakeholders, this role is currently not clear
and this should be addressed.

6. FUNDING FOR PROGRAMMES TO REMOVE BARRIERS TO HIV AND TB SERVICES

To gather data on the amount of investment in programmes to address and remove human rights barriers to HIV and TB services in South Africa, a desk review and analysis of existing data sets were conducted as well as new data collection and key informant interviews. The combined results are presented below and show an overall increasing level of funding support for interventions to remove barriers, including in each of the seven programme areas and for approaches that integrated these within broader efforts. For this latter category, in many instances, particularly for national and provincial government expenditures, it was not possible to determine the proportion of funding directed towards human rights or gender-related components. The analysis shows that, nevertheless, in terms of direct funding support for human rights interventions, the Global Fund and PEPFAR are the primary sources.

6.1. Expenditure analysis for the HIV Investment Case

With regard to previous levels of investment before 2016, a country-wide expenditure analysis exercise for the South African Investment Case for HIV, carried out in 2014, found that expenditure on human rights interventions was not discretely labelled in the government basic accounting system and was therefore difficult to track. The United States government (USG) in its funding programmes also did not discretely label expenditure for human rights interventions. What the analysis did show was that expenditure for key populations programme areas averaged approximately US\$29 million per year from the 2011/12 to 2013/14 financial periods, with government being responsible for 52% and PEPFAR 41% over that period. Global Fund resources largely made up the balance and were the only source where expenditures for interventions for HIV-related stigma reduction, and for SGBV and gender equity, were specifically identified. These averaged approximately US\$306,000 per year. It should be noted that the analysis did not include expenditure from other sources, such as other health development partners or foundations, meaning that the amount of direct funding could have been higher.

6.2. External funding for interventions to remove barriers

Funding data collected for this assessment gives a more detailed picture and shows a total investment in human rights or gender-related interventions of US\$19.4 million in 2016, rising to US\$22.7 million in 2017. While this may signal an increase in support, the assessment could not confirm this as it was unable to track all sources of funding for both years. **Table 2**, below, shows funding levels for HIV for each year by programme area.

Table 2: Total HIV funding by programme area and year (2016-2017)

Programme Area	Funds for 2016 (US\$)	Funds for 2017 (US\$)	Total (US\$)	%
Stigma and discrimination reduction for key populations	933 514	2 320 638	3 254 152	16%
Training for HCW on human rights and medical ethics related to HIV	499 462	477 331	976 793	5%
Sensitization of law-makers and law enforcement agents	48 967	136 457	185 424	1%
Legal literacy ("know your rights")	10 414	13 886	24 300	0%
HIV-related legal services	306 881	1 127 627	1 434 508	7%
Reducing discrimination against women in the context of HIV	6 732 314	7 587 873	14 320 187	71%
TOTAL HIV	8 531 552	11 663 812	20 195 364	100%

Funding for HIV-related stigma reduction programmes supported targeted activities for key populations, and for adolescents and young people, using a variety of delivery modalities, such as district-level programming, peer outreach, advocacy and social mobilisation, and training. Funding for the reduction of discrimination against women in the context of HIV supported prevention programming for adolescent girls and young women in and out of school and in tertiary institutions, as well as SGBV programmes, including advocacy activities. **Table 3**, below, shows funding levels for TB for each year by programme area.

Table 3: Total TB funding by programme area and year (2016-2017)

Programme Area	Funds for 2016 (US\$)	Funds for 2017 (US\$)	Total (US\$)	%
Stigma and discrimination reduction for TB	473 552	440 567	914 119	61%
TB programs in prisons and other closed settings	546 245	36 450	582 695	39%
TOTAL TB	1 019 797	477 017	1 496 814	100%

Funding for TB programmes supported stigma reduction in mines, mining communities and informal settlements, and combination prevention programming in prisons.

The data collected for the assessment also showed where this funding came from. **Table 4**, below, illustrates these results for HIV.

Table 4: Funding for HIV by source and year (2016-2017)

Funder	Funds for 2016 (US\$)	Funds for 2017 (US\$)	Total (US\$)	%
Aidsfonds	114 388	211 188	325 576	2%
Comic Relief	124 649	137 770	262 420	1%
European Union	-	277 428	277 428	1%
Global Fund	5 083 894	6 502 570	11 586 464	57%
OSISA/ SANAC	1 050 812	_	1 050 812	5%
United States Government	2 743 357	3 216 930	5 960 287	29%
Mixed	597 075	412 782	1 009 857	5%
TOTAL	9 714 176	10 758 668	20 472 843	100%

As shown in the table, USG/PEPFAR and the Global Fund contributed 86% of the identified funding in both years. The amount of US\$11 586 464 under Global Fund includes US\$1 496 814 for TB programmes. The analysis captured four other sources of funding. Response rates from key informants for this component of the baseline assessment were low, meaning that there are likely more sources that have not yet been identified. Even if these data were available, however, it is most likely that the predominance of USG/PEPFAR and Global Fund sources would remain.

6.3. Government investments in human rights programmes

The South African Government implements a number of programmes that may well contain elements under some or all of the seven programme areas; however, as already noted, government budgets and expenditure reporting do not provide this level of detail. The assessment was therefore only able to identify a few programme areas for HIV and TB where there were likely to be relevant investments. The results are shown in **Table 5**, below.

Table 5: Annual budgets by department and government programme area (2016-2017)

Ref	Department	Programme	Funds in 2016/17 (US\$)	Funds in 2017/18 (US\$)	Total (US\$)	%
1	Justice and Constitu- tional Development	Constitutional Development	273 654	283 408	557 062	0,2%

2	National Basic educa- tion	Partnerships in Education: HIV Life Skills	1 684 615	1 884 615	3 569 231	1%
3	Provincial Education	HIV Life Skills: Com- prehensive sexuality education, life skills, care and support	17 757 615	18 869 846	36 627 462	11%
4	Provincial Health	Health Communication		8 923 077	8 923 077	3%
5		HIV and AIDS - High Transmission Areas	0	8 692 308	8 692 308	3%
6	HIV and AIDS - Regional Training Centres		0	13 307 692	13 307 692	4%
7	National Social Development	vention care and sun-		7 908	14 385	0,00 4%
8	Provincial Social Development	vention care and cun-		65 462 385	128 301 169	38%
9		Victim Empowerment	34 037 154	36 771 408	70 808 562	21%
10		Women Development	3 982 077	4 102 777	8 084 854	2%
11		Youth Development	22 796 501	21 155 273	43 951 774	13%
12	Women	Commission for gender equity	5 376 923	6 023 077	11 400 000	3%
13		Transformation, justice, economic & social empowerment, leadership		1 284 615	2 092 308	1%
	Grand Total		149 561 493	186 768 388	336 329 881	100 %

Source budgets converted at US\$1=ZAR13.

The data in the table reflect a significant investment on the part of national and provincial governments in HIV and TB-related programming at US\$336 million over the two-year period (). However, this may be misleading in the context of this analysis as it cannot be known how much of this amount directly supports interventions to address and remove human rights barriers as they have been identified throughout this assessment. For example, provincial DOHs implementing the HTA programme (line 5) transfer approximately 45% of their annual budget to NGOs but the analysis did not identify which NGOs receive these funds nor what proportion supports activities that address human rights barriers to services. Key informants were of the view that at least some of the funds do support such activities, however.

As another example, there are the regional training centres (line 6) which, as described previously, may include content on human rights and medical ethics related to HIV and TB in their training programmes. Furthermore, the DOH, through its provincial counterparts, delivers a health communication campaign with an emphasis on HIV and TB amongst other health topics (line 4). Called "Phila", the campaign includes some (limited) content on stigma and discrimination reduction against key populations and against women in the context of HIV (Phila, 2017). A review of the annual performance plans of provincial DSDs showed that a number of them address stigma and discrimination and human rights issues with key populations as part of their HIV programmes (line 8). The Women's Development Units in some provincial DSDs conduct dialogues with vulnerable women on stigma and discrimination in priority districts (line 9). Finally, as noted in **Section 4.5.8**, above, the DOJCD supports 55 TTCs country-wide (line 1).

What all of these items illustrate is that, at least from the perspective of budgeting and planning, it may be that an important amount of total resources currently supporting efforts to address human rights concerns in the context of HIV or TB comes from government sources. However, as has been outlined elsewhere in this report, whether or not the programmes and interventions that are ostensibly meant to be supported by these funds are either implemented or implemented effectively remains a subject of on-going debate.

Overall, what this analysis of investments shows is that the amount of current or potential resources available to support programmes to address human rights barriers to HIV and TB is substantive, amounting to at least US\$20 million in 2017 from external sources alone. As has been noted, the largest proportion of these funds supports programmes for adolescent

girls and young women which are broad in scope and, although they contain components that address human rights barriers for this group, the amount of resources attached to these components could not be determined. As a result, this may lead to an over-estimation of current human rights investments.

The analysis also shows that there appears to be a degree of fragmentation amongst external funders, government departments and implementers in the different sectors, including the civil society sector. As has been highlighted elsewhere, current efforts to address barriers are hampered by the lack of an overall, nationally coordinated approach and this no doubt affects how such efforts are funded.

7. PROJECTION OF FUNDING NEEDS FOR COMPREHENSIVE PROGRAMMES

The final component of the assessment was to estimate the five year cost of implementing the comprehensive approach. A high level summary for HIV is shown in **Table 6**, below. The detailed activities are described in **Annex A** and the detailed costing is included in **Annex C**.

Table 6: Estimated funding needs for HIV 2017-2021 (US\$)

Table 6: Estimated funding needs for HIV 2017-2021 (US\$)							
Human rights and stigma Pro- gramme	Year 1	Year 2	Year 3	Year 4	Year 5	Total	%
	1 car 1	1 cai 2	Teal 3	1 cai 4	Teal 5	Total	/0
PA 1. Stigma and discrimi- nation reduc- tion for key populations	1 714 403	1 373 551	1 234 341	1 701 982	1 084 377	7 108 654	24%
PA 2. Training for health care workers (HCW) on hu- man rights and medical ethics related to HIV	410 088	215 336	169 951	202 724	93 056	1 091 154	4%
PA 3. Sensitization of law- makers and law enforce- ment agents	469 812	316 434	304 981	400 104	287 037	1778 368	6%
PA 4. Legal literacy ("know your rights")	293 225	272 464	265 543	265 543	265 543	1 362 318	5%
PA 5. HIV-re- lated legal ser- vices	1 810 612	1 721 343	1 664 581	1 649 687	1 649 687	8 495 910	29%
PA 6. Monitoring and reforming laws, regulations and policies relating to HIV	739 861	745 116	745 116	704 604	704 604	3 639 301	12%

PA 7. Reducing discrimination against women in the context of HIV	-06	0-6					04
	786 594	734 806	596 617	423 782	722 142	3 263 940	11%
Other activities (evaluation and research)	183 781	591 189	647 971	497 061	870 193	2 790 195	9%
Grand Total	6 408 376	5 970 237	5 629 100	5 845 486	5 676 639	29 529 839	100%

Given the analysis, above, of available funding to support programmes to remove barriers to HIV services, it appears that, should this level of investment be sustained, South Africa is highly likely to be able to mobilise sufficient resources to implement the five year comprehensive programme.

A high level summary for TB is shown in **Table 7**, below. The detailed activities are described in **Annex B** and the detailed costing is included in **Annex C**.

Table 7: Estimated funding needs for TB 2017-2021 (US\$)

Programme	Year 1	Year 2	Year 3	Year 4	Year 5	TOTAL	%
Area							
PA 1: Reduc-							
ing stigma							
and discrimi-							
nation							
	570 320	526 809	421 584	345 988	345 988	2 210 689	20%
PA 2: Reduc-							
ing gender-re-							
lated barriers							
to TB services							
	107 664	140 006	140 006	140 006	140 006	667 688	6%
PA 3: TB-re-							
lated legal ser-							.07
vices	30 691	15 346	6 138	6 138	6 138	64 451	1%
PA 4: Moni-							
toring and re-							
forming poli-							
cies, regula-							
tions and laws							
that impede TB services							-07
	151 200	151 200	151 200	151 200	151 200	756 001	7%
PA 5: Know							
your TB-re-							4 0/
lated rights	42 320	33 437	24 553	24 553	24 553	149 416	1%
PA 6: Sensiti-							_
zation of law-							
makers, judi-							
cial officials							
and law en-							
forcement agents							6%
agents	143 042	125 274	143 042	125 274	125 274	661 907	

search) Grand Total	380 397	140 066	455 289	251 177	233 067	1 459 996	13% 100
Other activi- ties (evalua- tion and re-							
011 111	404 617	575 436	554 462	554 462	550 018	2 638 996	23%
PA 10: Programs in prisons and other closed settings							
PA 9: Mobiliz- ing and em- powering pa- tient and com- munity groups	212 210	336 979	336 979	336 979	336 979	1 560 127	14%
PA 8: Ensur- ing confiden- tiality and pri- vacy	22 097	9 040	9 040	9 040	9 040	58 256	1%
PA 7: Training of health care workers on human rights and ethics re- lated to TB	199 798	164 263	164 263	326 017	148 343	1 002 684	9%

As the assessment identified a much lower investment in current programmes to reduce human rights barriers to TB services, South Africa will have some distance to cover to mobilise sufficient resources to implement that five-year comprehensive programme. However, the catalytic investment available to the country under the 2018-2020 funding cycle will at least provide a starting point for being able to leverage additional resources from both domestic and external sources.

8. LIMITATIONS

The assessment encountered some limitations:

- Some important stakeholders were not able to participate in data collection due to competing priorities, particularly during the time of year when the assessment took place (programme year-ends). They included representatives from some key government stakeholders, particularly the DCS as well as the DOH, particularly at provincial levels. As a result, important perspective on human rights barriers and on the effectiveness of current efforts to address them may be missing from the analysis. Stakeholders that could not participate also included a number of bilateral partners and, as a result, the description of current efforts to address and remove barriers may not include what these entities are currently funding or undertaking directly.
- There were some specific limitations and challenges to the collection of financial data:

- · It appeared that a number or organisations felt that the information requested was too sensitive to share even though it was indicated in the invitation messages that the data would be consolidated and anonymised at the implementer level.
- Some organisations appeared to take the position that the benefit of completing the exercise was not worth the level of effort required, given other pressures on them.
- Most funders and intermediaries appeared to be unable to disaggregate their investments in combination prevention interventions to the level where funding for programmes addressing human rights barriers could be identified.
- Finally, as the analysis has noted in several places, there is a large gap in current and comprehensive quantitative data on a number of the human rights barriers identified by the assessment. As a result, there may be an over-reliance on individual or anecdotal accounts or perspectives which may not, in some cases, be an accurate reflection of an overall, country-wide trend.

9. NEXT STEPS

This baseline assessment will be used as the basis for dialogue and action with country stake-holders, technical partners and other donors to scale up comprehensive programs to remove human rights barriers to HIV and TB services in South Africa. Towards this end, the Global Fund will arrange a multi-stakeholder meeting in the coming months in order to share the assessment results for consideration and discussion towards using existing opportunities to include and expand programs to remove barriers to services. Depending on the country's status in the funding cycle, these opportunities might comprise matching fund applications, funding proposal development, grant negotiation, grant implementation and reprogramming.

The Global Fund will also use the assessment as a basis to support country partners to develop a 5-year plan to move from the current level of programming to remove barriers towards the achievement of a fully comprehensive approach. In this 5-year plan, it is envisioned that the country will set priorities as well as engage other donors to fully fund the comprehensive programmes involved. Finally, in order to build the evidence base regarding programmes to reduce barriers to HIV and TB services, the Global Fund will commission follow up studies at mid- and end-points of the 2017-2022 strategy to assess the impact on access to HIV and TB services of the expanded programmes put in place under the 5-year plan.

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ANNEX A: COMPREHENSIVE PROGRAMMES TO REDUCE BARRIERS TO HIV SERVICES

Ref	Programme Area	Ref	Activity	Assumptions	Year 1 (US\$)	Year 2 (US\$)	Year 3 (US\$)	Year 4 (US\$)	Year 5 (US\$)	Total (US\$)
1	Stigma and dis- crimination re- duction	1,1	Establish a national Stigma and Discrimination Reduction Working Group to develop and lead a national Stigma and Discrimination Reduction Strategy	Technical support to develop the TOR and to support strategy development. Operational support for working group.	50 164	50 164	50 164	50 164	50 164	250 819
		1,2	Develop and implement a national stigma reduction communications campaign.	Undertake as a partnership with private sector. Incor- porate KP REACH materi- als.	983 396	721 842	656 189	656 189	590 536	3 608 153
		1,3	Scale up interventions which support antistigma champions.	Support for national and provincial level champions. Training and honoraria.	36 515	32 811	32 811	32 811	32 811	167 759
		1,4	Strengthen the technical and operational capacities of key population and PLHIV networks to deliver integrated programmes to address stigma, discrimination and violence against their members at community level	Technical support, training, programme development, operational support, evaluation.	465 021	471 811	387 205	308 059	331 961	1 964 056
		1,5	Support rapid assess- ments, surveys and eval- uations to inform stigma reduction interventions	Undertake new Stigma Index Survey in Year 4 with revisions to design to ensure full participations of KPs who are PLHIV. Also, undertake focussed investigations.	-	-	-	570 370	-	570 370
		1,6	Strengthen psycho-social support programmes to address self-stigma	Technical support for assessment and national action planning and monitoring process.	78 905	67 857	78 905	67 857	78 905	372 429
		1,7	Strengthen HTA Programme		63 365	29 067	29 067	16 531	-	138 030

		1,8	Conduct situational assessment on access to services for foreign migrants and development action plan.		37 037	-	-	-	-	37 037
			Subtotal		1 714 403	1 373 551	1 234 341	1 701 982	1 084 377	7 108 654
2	Training for HCW on human rights and medi- cal ethics.	2,1	Scale up the implementa- tion of the Health Work- ers for Change training to cover more health facili- ties.	Based on WHO training programme. Delivered through Regional Training Centres.	-	-	-	-	-	-
		2,2	Deliver key population sensitization training (using the I-TECH manual) through the Regional Training Centres to improve coordination of this work and to ensure country-wide coverage.	Operational support to deliver training.	32 538	25 172	15 965	15 965	15 965	105 606
		2,3	Equip key-population-led CSOs with the technical and operational capaci- ties to provide district- level sensitization train- ing and mentorship for health facilities.	Standardisation of engagement materials/guides. Operational support to conduct training/sensitisation work in communities.	144 954	72 477	72 477	72 477	72 477	434 861
		2,4	Strengthen and scale-up local collaborations between health facilities and CSOs, especially those that are key-population-led, for programme components such as outreach, screening and referrals, peer navigation, or adherence support	Delivered through CSS programmes.	49 236	36 178	-	-	-	85 413
		2,5	Review training curricula for all health and social services professions to assess whether training curricula are adequately	Technical consultancy to undertake review and to develop recommenda- tions/action plan as well as	16 667	-	-	16 667	-	33 333

		2,6	supporting the develop- ment of competencies in diversity, sexuality, gen- der and human rights Scale up provision of	proposal for adaptation/change of curricula. Service contract for exter-						
		2,0	Critical Diversity Literacy training to staff in rele- vant departments of uni- versities, colleges and other health training in- stitutions	nal provider to relevant institutions.	4 614	4 614	4 614	4 614	4 614	23 068
		2,7	Evaluate changes in atti- tudes/quality of service (baseline & follow-up). (part of integrated sensi- tisation training pro- gramme)		74 074	-	-	93 001	-	167 076
		2,8	DENOSA to scale up its life skills/values clarifica- tion training/support for nurses.		88 006	76 895	76 895	-	-	241 796
			Subtotal		410 088	215 336	169 951	202 724	93 056	1 091 154
3	Sensitisation of law-makers and law enforce- ment agents	3,1	Undertake a focused assessment on the role of the judiciary and traditional leaders in potentially contributing to barriers to services for key populations and develop an action plan to address the results. Support SANAC to take a	Technical consultancy for comprehensive, country-wide assessment. Support for validation and action planning to address results. Additional operational sup-	410 088 35 212	215 336 -	169 951 -	202 <i>7</i> 24	93 056 -	35 212

		3,3	Scale up efforts to bring about positive shifts in knowledge, attitudes and practices of the police re- garding key and vulnera- ble populations and their need for HIV services	National level leader- ship/coordination mecha- nism. Technical and opera- tional support for roll-out of training programmes.	344 039	278 181	230 090	371 182	230 090	1 453 582
		3,4	Continue work to train and sensitise policy-mak- ers, police and the judici- ary on the importance of harm reduction for PWID.	National level leader- ship/coordination mecha- nism. Technical and opera- tional support for training, sensitisation and advo- cacy/engagement activities.	40 416	3 778	40 416	3 778	40 416	128 803
		3,5	Strengthen the operational and technical capacity of local key-population-led CSOs to facilitate and lead 'constructive engagement' interventions with local police as well as local traditional leaders.	Technical assistance, standardised materials/ap- proaches, and operational support for local commu- nity initiatives.	22 212	17 944	17 944	8 613	-	66 713
		3,6	Expedite the establishment of a National Policing Board, as mandated in the National Development Plan.	Advocacy campaign.	11 403	-	-	-	-	11 403
			Subtotal		469 812	316 434	304 981	400 104	287 037	1 778 368
4	Legal literacy	4,1	Support PLHIV networks and key-population-led CSOs to scale up activi- ties to improve knowledge regarding	Additional technical/operational support at community level for peer educators/others.	121 954	101.054	121 954	121 954	121 954	609 771
			HIV-related human rights for individuals in their respective communities.		121 934	121 954	121 934	701	701	

		4,3	Ensure that paralegals and other similar types of individuals working in CSOs, such as NADCAO, have full knowledge and can provide assistance regarding HIV-related legal and human rights.	Additional training/sensitisation programmes for relevant entities.	13 841	20 762	13 841	13 841	13 841	76 126
		4,4	Strengthen the civic edu- cation outreach pro- grammes of Legal Aid South Africa, and the DOJCD	Increased operational support for existing structures.	126 672	126 672	126 672	126 672	126 672	633 360
			Subtotal		293 225	272 464	265 543	265 543	265 543	1 362 318
5	HIV-related legal services	5,1	Extend and subsequently promote the role of Legal Aid South Africa to provide legal support and representation to all people (including key population constituencies, not only PLHIV) who have experienced HIV-related legal or human rights challenges and who qualify for services.	Communications and outreach activities within communities. National communications campaign.	33 939	-	-	-	-	33 939
		5,2	Provide increased financial and technical support to NADCAO members so that Community Advice Offices and their paralegals can undertake outreach, and can reach more PLHIV and other individuals from key and vulnerable populations with their services	Additional operational support.	422 240	422 240	422 240	422 240	422 240	2 111 200
		5,3	Provide a cadre of peer educators working with key populations in local communities with training and support to work	Recruitment, training and deployment. On-going mentoring/supervision.	813 198	797 852	788 645	788 645	788 645	3 976 985

			as human rights defend-							
		5,4	ers or paralegals. Linked to above point, develop a national hu- man rights scorecard sys- tem		17 767	8 884	-	-	-	26 651
		5,5	Implement local-level human rights violations reporting tool. REACT (or similar) for KVP net- works		312 965	299 631	272 009	272 009	272 009	1 428 624
		5,6	With the scale up of PWID programmes, en- sure that at each site, a peer educator is trained to monitor and respond to human rights viola- tions		3 845	3 845	3 845	1	-	11 534
		5,7	Sensitize and strengthen the capacity of SAHRC respond to HIV related Human Rights violations and conduct trainings.		39 865	22 098	11 049	-	-	73 011
		5,8	Support Human Rights Commission to monitor access to justice for PLHIV and other KPs.		53 460	53 460	53 460	53 460	53 460	267 298
		5,9	Contribute to paralegals from Legal Aid South Af- rica and NADCAO to con- duct HIV-related legal education, mediation, support.		113 333	113 333	113 333	113 333	113 333	566 667
			Subtotal		1 810 612	1 721 343	1 664 581	1 649 687	1 649 687	8 495 910
6	Monitoring and reforming laws and policies	6,1	Establish a national mechanism for the consolidation, auditing and analysis of HIV-related human rights violations towards PLHIV and other key and vulnerable populations.	Support for a 'secretariat' and for web-based reporting and monitoring mechanism.	242 011	278 092	278 092	278 092	278 092	1 354 377

	1		I a l l DEAL	0 1 1 10			I	I		1
		6,2	Scale up the REAct model to more provinces to support the national monitoring mechanism.	Operational support for CSOs in communities and stipends for 'REActors'; web-based reporting plat- form linked to national mechanism above.	-	-	-	-	-	-
		6,3	Develop and implement a national HIV and TB Hu- man Rights Accountabil- ity Scorecard.	Technical support for design, piloting and launch. Ongoing support for data collection, analysis and reporting linked to 'secretariat' above.	17 767	-	-	-	-	17 767
		6,4	Sustain the collective ef- fort to revise the provi- sions in Sexual Offences Act regarding sex work	Technical and operational support for groups working for law and policy change.	15 279	15 279	15 279	15 279	15 279	76 396
		6,5	Promote consultation and collaboration be- tween government and civil society to advance drug-related laws and policies which are evi- dence-based and reduce harms against drug users, including harms related to HIV	Support for dialogue/engagement opportunities, materials development and advocacy activities.	115 435	102 377	102 377	71 686	71 686	463 560
		6,6	Increase capacity of KP networks to be more active in law and policy reform.		300 658	300 658	300 658	300 658	300 658	1 503 292
		6,7	Increase the technical and operational capacity of more key-population-led networks and organisations to participate in policy-making processes and to be more effective at lobbying and advocacy.	Training and technical support for skills development. Funds for coordination, engagement, advocacy activities.	48 710	48 710	48 710	38 889	38 889	223 908
			Subtotal		739 861	<i>7</i> 45 116	745 116	704 604	704 604	3 639 301
7	Reducing dis- crimination	7,1	Strengthen and sustain the TCCs.	Technical support for a functional review and rec-	33 146	33 146	-	-	-	66 293

against adoles- cent girls and young women in the context of HIV			ommendations for stream- lining/sustainability. Addi- tional operational support based on recommenda- tions.						
	7,2	Roll-out other community-based, well-coordinated models to support survivors of SGBV and other forms of physical violence that can be implemented in areas where there are no TCCs.	To be discussed.	476 488	313 212	343 903	313 212	611 572	2 058 386
	7,3	Critically evaluate the components of combination HIV interventions for adolescent girls and young women that address removing barriers to access, uptake and retention across the continuum of HIV interventions (including adherence to PEP, and PMTCT, for example).	Technical support for comprehensive review and development action and revised programme models where relevant.	18 600	18 600	18 600	18 600	18 600	93 000
	7,4	Sustain interventions involving government and civil society partners to remove barriers for adolescents and young people to access and remain in HIV services.	Additional operational support.	42 419	127 256	42 419	42 419	42 419	296 931
	7,5	Empower more adolescent girls and young women to be advocates and community mobilisers regarding ending violence and other harmful cultural practices that limit or deny their SRHR.	Recruitment, training and deployment of peers in communities. Ongoing support for mentoring and security/protection.	37 429	37 429	37 429	37 429	37 429	187 144
	7,6	Provide additional training and support to a cadre of peer educators to	Recruitment, training and deployment in communities. Ongoing support for	130 021	130 021	130 021	-	-	390 064

			be able to recognise and	mentoring and secu-						
			respond to individuals in	rity/protection.						
			local communities who							
			are victims of gender-							
			based violence but are re-							
			luctant to seek support							
		7,7	Sustain and scale-up in-	Additional technical and						
			terventions that provide	operational support.						
			comprehensive support		10.101	10.404	0.4.0.4.	40.400	10.100	145 472
			to individuals from key populations that experi-		48 491	48 491	24 245	12 123	12 123	140 4/2
			ence gender-based vio-							
			lence in all its forms							
8	Other activities	7,8	Ensure that programmes training HCWs workers on the health needs of key populations include sufficient content on providing medical and psychological support to individuals who have experienced gender-based violence. Subtotal Support evaluations of	Technical support for situational assessment and for development of revised training materials as required. Support for a range of eval-	- 786 594	26 651 7 34 806	- 596 617	- 423 782	- 722 142	26 651 3 263 940
8	Other activities		interventions to address human rights barriers	uation/studies from country-wide to local community-based.	-	407 407	185 185	407 407	407 407	1 407 407
		8,2	Conduct mid- and end- term follow-up baseline assessments for HIV and TB		-	-	279 004	-	279 004	558 009
		8,3	Support structures and SANAC to coordinate and monitor implementation of the comprehensive plan to address barriers.	Use budget/assumptions for this baseline.	183 781	183 781	183 781	89 653	183 781	824 779
			Subtotal		183 781	591 189	647 971	497 061	870 193	2 790 195

ANNEX B: COMPREHENSIVE PROGRAMMES TO REDUCE BARRIERS TO TB SERVICES

Ref	Pro-	Ref	Activity	Assumptions	TO TUBE							
Kei	gramme Area	Kei	Activity	Assumptions	Year 1 (US\$)	Year 2 (US\$)	Year 3 (US\$)	Year 4 (US\$)	Year 5 (US\$)	Total (US\$)		
1	Reducing stigma and discrimina- tion	1.1	Develop a multi-year action plan to reduce stigma and discrimination	Technical support to develop the TOR and to support strategy development. Inception and validation meetings (2 days 30 pax?)	43 511	-	-	1	-	43 511		
		1.2	As part of the action plan, put in place a national co- ordinating mechanism for TB stigma reduction.	Operational support for coordinating mechanism (SANAC focal point and bi-annual meetings for 25 people)	50 164	50 164	50 164	50 164	50 164	250 819		
		1.3	Sustain country-wide programmes to raise awareness about TB and to reduce stigma and discrimination.	Technical and operational support for national/provincial communications/IEC campaigns.	124 604	124 604	93 453	62 302	62 302	467 264		
		1.4	Sustain and expand interventions that mobilise communities to understand and reduce stigma and discrimination	Community activities in districtsIEC, events, etc.	233 523	233 523	233 523	233 523	233 523	1 167 613		
		1.5	Scale-up interventions to address dual stigma.	Technical support to review current interventions and to develop proposals for improvement. Funds to develop/pilot adapted interventions.	44 444	44 444	44 444	-	-	133 333		
		1.6	Scale-up qualitative research on TB and TB/HIV stigma, particularly selfstigma.	Technical and operational support .	74 074	74 074	-	-	-	148 148		
			Subtotal		570 320	526 809	421 584	345 988	345 988	2 210 689		
2	Reducing gender- based ineq- uity	2,1	Scale-up up efforts in communities to improve access to social support for TB-affected house- holds, including for disa- bility grants.	Technical support/training for CSOs already working in communities?	32 499	14 732	14 732	14 732	14 732	91 426		

		2,2	Strengthen advocacy work for mining communities to ensure that mining companies support house- holds of TB-affected min- ers.	Additional support for Sonke, others, to work in mining communities.	75 165	125 274	125 274	125 274	125 274	576 262
			Subtotal		107 664	140 006	140 006	140 006	140 006	667 688
3	PA 3: TB- related le- gal services	3,1	Provide training or technical support, where needed, to ensure that legal service providers can address TB-specific legal concerns.	Support for training/mentoring as required.	30 691	15 346	6 138	6 138	6 138	64 451
			Subtotal		30 691	15 346	6 138	6 138	6 138	64 451
4	PA 4: Monitoring and reforming policies, regulations and laws that impede TB services	4,1	Sustain efforts by civil society to monitor human rights trends in the context of TB.		125 274	125 274	125 274	125 274	125 274	626 372
		4,2	Sustain support for strategic litigation.		25 926	25 926	25 926	25 926	25 926	129 630
			Subtotal		151 200	151 200	151 200	151 200	151 200	756 001
5	PA 5: Know your TB-related rights	5,1	Sustain and expand community-level activities to promote human rights literacy in the context of TB, particularly for issues of privacy, confidentiality and autonomy.	Additional technical and operational support at community level. Can be linked to 1.4.	17 767	8 884	-	-	-	26 651
		5,2	Continue to include TB- related human rights components in commu- nity-based rights literacy programmes for HIV	No additional cost.	-	-	-	-	-	-
		5,3	Increase the capacity of community-based HIV entities to promote TB hu- man rights literacy	Training in provinces (2 days) for implementers. Materials development?	24 553	24 553	24 553	24 553	24 553	122 764
			Subtotal		42 320	33 437	24 553	24 553	24 553	149 416

6	Sensitisation of law- makers and law enforce- ment agents	6,1	Integrate content related to TB in the sensitisation and engagement activities with law enforcement agents and others, de- scribed under HIV, above.	Technical consultancy to undertake review and to develop recommenda- tions/action plan for needed changes.	17 767	-	17 767	-	-	35 535
		6,2	Sustain civil society advo- cacy for proper judicial oversight of prison condi- tions.	Advocacy campaign. Support for planning, coordination, monitoring.	125 274	125 274	125 274	125 274	125 274	626 372
			Subtotal		143 042	125 274	143 042	125 274	125 274	661 907
7	Training of health care workers	7,1	Review training curricula and training processes to ensure that content on TB-related human rights is included and that it re- ceives enough emphasis in training programmes.	Technical consultancy to undertake review and to develop recommenda- tions/action plan as well as proposal for adapta- tion/change of curricula.	17 767	-	1	177 674	-	195 441
		7,2	Scale up work by civil society to improve accountability and action on the part of DOH at national and provincial levels for safe working conditions for HCWs	Additional technical and operational support for advocacy campaigns and engagement activities with policy makers (like what TB Proof and TAC do, for example).	141 194	141 194	141 194	125 274	125 274	674 132
		7,3	Address TB-related stigma amongst HCWs as part of the multi-year ac- tion plan described above.	Technical/operational support for focussed interventions for HCWs.	40 836	23 068	23 068	23 068	23 068	133 110
_		_	Subtotal		199 798	164 263	164 263	326 017	148 343	1 002 684
8	PA 8: Ensuring confidentiality and privacy	8,1	Support additional participatory action and operational research, and pilot programmes for new approaches to TB care that empower patients and respect their privacy and confidentiality.	Technical and operational support for research pro- jects and programme pi- lots.	22 097	9 040	9 040	9 040	9 040	58 256
			Subtotal		22 097	9 040	9 040	9 040	9 040	58 256
9	PA 9: Mo- bilizing	9,1	Sustain and expand com- munity-level efforts to support and empower	Peer educators in districts, support groups.	187 155	311 924	311 924	311 924	311 924	1 434 852

	and empowering patient and community groups		people living with TB to challenge and overcome stigma.							
		9,2	Support civil society to monitor the implementa- tion of the new public health regulations, partic- ularly the aspect of man- datory measures.	Operational support for monitoring and advocacy activities.	25 055	25 055	25 055	25 055	25 055	125 274
			Subtotal		212 210	336 979	336 979	<i>336 979</i>	<i>336 979</i>	1 560 127
10	PA 10: Programs in prisons and other closed settings	10,1	Support NGOs to scale-up sensitization and TB literacy trainings with DCS members and inmates to improve facility-level mobilization, collaboration and support for TB control in prisons.	Additional technical and operational support for current implementers to continue work (see narrative report section 5.5.13)	81 517	75 105	71 899	71 899	71 899	372 319
		10,2	Strengthen coordination mechanisms between the DCS and other government departments (such as the DOH and SAPS) and stakeholders (NGOs) to improve the effectiveness and impact of TB interventions within prisons.	Support for coordination mechanism (quarterly meetings?) led by DCS.	35 041	35 041	35 041	35 041	35 041	175 206
		10,3	Provide HCWs in prisons with full occupational health support to reduce their risk of TB exposure and to support them with full benefits should they acquire TB disease	Advocacy campaign for policy change.	22 212	22 212	4 444	4 444	-	53 313
		10,4	Scale up programmes led by former prisoners that support newly released peers to transition back to communities.	Technical and operational support to establish/ex- pand existing mecha- nisms.	190 682	317 804	317 804	317 804	317 804	1 461 896

		10,5	Scale-up parolee and civil- society-led advocacy for prison reform with a pri- ority on improving basic conditions in prisons for reduction of TB and other health risks.	Technical and operational support for advocacy campaign and improved oversight processes .	75 165	125 274	125 274	125 274	125 274	576 262
			Subtotal		404 617	<i>575 4</i> 36	554 462	554 462	550 018	2 638 996
11	Other activities	11,1	Support evaluations of in- terventions to address hu- man rights barriers	Support for a range of evaluation/studies from country-wide to local com- munity-based.	333 333	93 001	408 225	204 113	186 003	1 224 676
		11,2	Support structures and SANAC to coordinate and monitor implementation of the comprehensive plan to address barriers.	Shared contribution to same intervention in HIV plan.	47 064	47 064	47 064	47 064	47 064	235 320
			Subtotal		380 397 2 242 259	140 066 2 208 815	455 289 2 397 51 7	251 177 2 261 796	233 067 2 061 567	1 459 996 11 230 210