

# Consultative Forum Report

## *Supporting the people of the HIV, AIDS & TB response*

NACOSA ANNUAL GENERAL MEETING, 30 NOVEMBER 2015



## INTRODUCTION

Funding, systems and plans are all important in achieving the global goal of ending AIDS by 2030 but it is people who ultimately influence the thrust of the AIDS response. UNAIDS's 90-90-90 treatment strategy acknowledges the importance of people in the attainment this goal, as does the Sustainable Development Goals Agenda, adopted by the United Nations General Assembly in September:

*“It is an Agenda of the people, by the people and for the people – and this, we believe, will ensure its success.”*

NACOSA's own experience has shown that it is a complex, multi-faceted and layered field of work that cuts across all areas of society – people and communities are therefore at the very centre of the HIV, AIDS and TB response.

If we are to end AIDS by 2030, we need 90% of people to be accessing services. There are also some ambitious new targets for combatting TB. Health Minister, Dr Aaron Motsoaledi, as Chair of the Stop TB Partnership Coordinating Board announced a 90-90-90 TB target:

- 90% of vulnerable groups screened
- 90% diagnosed and started on treatment
- 90% treatment success.

The NACOSA Consultative Forum at the 2015 Annual General Meeting therefore discussed:

### *Supporting the people of the HIV, AIDS and TB response*

The following questions were posed:

- How do we **support the people** and programs to be most effective on the ground?
- What are the **challenges** they face?
- How do we **prevent burnout** and **fatigue**?
- What are the most pressing **gaps in knowledge and skills**?
- What **strategies** can we employ to be more effective in our response?

Groups of people from NACOSA network organisations discussed and debated the issue, facilitated by NACOSA staff members. Input was also received on the topic by keynote speakers, Dithuso Monare from the Free State Department of Social Development and Dr Pren Naidoo, head of operational research at the Desmond Tutu TB Centre at Stellenbosch University.

The feedback from these discussions is summarised below and will be shared with SANAC and other relevant national structures so that the issues raised here can be heard by policy makers.

## SUPPORTING THE PEOPLE OF THE RESPONSE

In her keynote address, Dithuso Monare, HIV & AIDS Manager for the Free State Department of Social Development said:

*“In the ever-changing environment of the scourge of AIDS, some people get left behind, not because they are lazy, but because they are so absorbed in service delivery and trying to excel in it.”*

The discussion groups and keynote speakers all recognised the critical role people play in the HIV, AIDS and TB response and highlighted particular areas where we can better support not only the people affected and infected, but also those caring for them.

The following comments and suggestions were noted:

- Provide care, support and nutrition and promote healthy and positive living
- Continue with awareness campaigns on prevention and healthy living
- Target schools and provide health education to school kids; build life skills programmes in school time to address adolescent HIV prevalence.
- Training and development to provide broader knowledge; quarterly trainings for professionals and community based organisations (CBOs)
- Ensure staff and broader public understand policies and rights. Knowledge is power, it facilitates access.
- Use social media effectively especially of age-appropriate media
- Use existing resources to strengthen and support programmes
- Adequate resourcing of programmes
- Use existing structures to assist – for example church halls for testing and programmes
- Skills training and capacity building
- Networking and collaboration – less duplication of services
- A need to bring services to the people: mobile clinics, door to door and home visits, support groups and having after-hours and Saturday clinics to improve access for working people.
- Strengthen relationships between CBOs and stakeholders
- Invite faith based organisations (FBOs) to the consultative meetings and partnerships with them
- Invite traditional leaders to the meetings and partner with them
- Funding for NGOs and CBOs to do their work
- Funding for awareness programmes, especially on the radio
- Counselling
- Networking, collaboration and referrals
- Train the trainer, team building and other non-financial rewards for community workers
- Identify the gaps
- Allocate social workers to areas within a sub-district, for example one social worker to every three NPOs in the area.
- Contracting staff who were trained through NACOSA/NGOs
- Training people who will still stay committed to the organisation and not leave once qualified.
- Incorporate learning into day-to-day programmes
- Regular communications to develop effective strategies
- Need to provide continuous training on HIV, AIDS and TB trends, on interventions, management of organisations, information management systems and monitoring and evaluation.

- Encourage mobilization of communities to build the capacity of households and encourage child participation in planning through children’s dialogues and community conversations.
- Passion for work deliverables – this is more than just a job.

## CHALLENGES

Backing-up a NACOSA survey of member organisations in April, which found that funding and resource issues are by far the biggest challenges facing the sector, every single group at the consultative forum mentioned **funding and resources** as one of the most pressing challenges and the negative impact this has on services:

*“Service points are understaffed so staff are burnt out resulting in them being edgy with patients.”*

In addition to funding and resource challenges, the groups identified the following:

- Stigma and discrimination is still very rife in communities
- People’s attitudes to HIV (living carelessly)
- Attitudes of health care workers in health facilities
- Substance abuse, teenage pregnancy
- Lack of skills, support and access to knowledge and training
- Over-crowded clinics
- Policies not implemented or poor application of existing policies and legislation
- Professionals don’t understand the work of NGOs
- High prevalence amongst adolescents
- CBOs not involved adequately
- Poor relationships between CBOs and clinics/health professionals
- Government not always partnering with local NPOs
- Getting referrals
- Government grant ends when CD4 goes above 350
- High turnover of staff because of low stipends
- Increase in responsibilities without increase in rewards
- Gang violence impacts on delivery of services

*“Community based workers are over-worked and prone to burn-out”*

- Lack of inter-sectoral communication
- Lack of knowledge about TB
- Lack of commitment
- Female vs male care workers in communities – need more male care workers

Organisations from the Free State were posed the consultative forum questions by Dithuso Monare before the AGM and she fed back the following responses:

- No sustainable sources of funding
- High turnover of skilled and experienced workers who move to government which provides better remuneration and incentives.
- Apathy/helplessness of communities they serve
- No stakeholder collaboration, everyone working in a silo and not making impact

- Noncompliance of organisations or individuals in an organisation which leads to the collapse of the services.
- High rates of social ills (HIV, AIDS, TB, poverty, teenage pregnancy, gangsterism) – many organisations are not equipped to deal and/cope with these.
- Insufficient skilled workers and resources to build the capacity of organisations.
- No healthy partnerships between government and community organisations to deal with challenges facing the health and welfare sector.

## TB CONTROL

The challenge presented by TB in a country with a high HIV prevalence rate like South Africa was outlined by Dr Pren Naidoo in her keynote address. She said:

*“We haven’t mobilised community action. There needs to be a sense of common responsibility.”*

Dr Naidoo identified the following challenges for TB control:

- An integrated approach
  - TB is the main cause of illness amongst those with HIV
  - HIV is the main driver of the TB epidemic
- Mobilisation of resources through partnerships
  - Individuals, communities, NGOs, government services
- Empowerment
  - Shared and individual responsibility

Dr Naidoo shared research which found that one of the major challenges is that people still don’t recognise the symptoms of TB:

*“I was having a terrible cough and I was sweating at night, but this did not ring an alarm for me, because I still thought this was just a fever and the change of season.”*

## PREVENTING BURN-OUT AND FATIGUE

All groups discussed and provided ideas and suggestions for preventing burn-out and fatigue amongst health and community care workers and those working in civil society, including:

- Care and support workshops
- Debriefing sessions for care workers and programme staff
- Continuous support and guidance from experts on programme areas
- Mentoring
- Counselling, particularly grief counselling
- Debriefing of field workers/staff once a month
- Teambuilding opportunities
- Open communication with management
- If well-trained, workers are less likely to suffer from burn-out
- Proper management of staff
- Rotation of staff where possible

- Support and supervision
- Wellness for staff and service providers
- Social events/gatherings/relaxing environment
- Social clubs: have a topic and support for each other – this gives carers a space for their own support

*“Awards, honorariums – recognition of outstanding contributions of the work done on the ground.”*

- Consultative meetings twice a year, have a formal dinner in districts
- Offer regular care for carer activities including motivation sessions and team building
- Focus and awareness throughout the year instead of only for events and deadlines
- Recruitment of volunteers
- Home based care included in service delivery at clinics
- Help desk at clinics
- Processes of how health services work should be explained to clients

## SKILLS AND KNOWLEDGE GAPS

To understand how to build the capacity of and provide support to people working in the HIV, AIDS and TB fields, we need to have a good understanding of what the gaps in skills and knowledge are. Discussion groups identified the following gaps:

- Supported supervision for careworkers

*“General knowledge on HIV programmes and in-depth information & knowledge, for example proper and correct messages on prevention, TB, STIs & HIV.”*

- Not keeping up with trends
- Education about discrimination/tolerance/diversity
- Up-to-date statistics per district showing where we are
- Carer diversity: lack of male carers and carers of different ages
- Education around stigma
- Information in most common languages
- Coaching and mentoring of staff

Dr Naidoo identified the following gaps in her presentation:

- Accountability
- Care for the carers

Organisations from Free State articulated these gaps:

- Insufficient knowledge to coordinate services at a local/implementation level
- Insufficient knowledge of policies and directives guiding programmes
- Insufficient knowledge of proper and accurate record keeping
- Insufficient knowledge of M&E and evidence-based recording
- Utilisation of community caregivers/community health workers (the difference between volunteerism and employment) and the issue of labour laws.
- Conflict management skills for managers within organisations
- Inability to write funding proposals
- Running support groups for children and for adults

## STRATEGIES

Although some groups ran out of time and were not able to address this part of the consultative forum topic, others were able to provide some interesting suggestions for strategies to support the people of the HIV, AIDS and TB response:

- Provide training in the various components of the programme areas

*“Improve remuneration for care workers – move away from stipends to salary.”*

- Create drama productions to involve young people
- Learning in a fun manner – working with schools
- Radio competitions on different topics
- Monthly dialogues and debates
- Allocate more financial resources
- Have a National Care for the Carer Day
- Start a quarterly carer forum to also include the police service
- More regular support groups which will result in smaller groups but also dates that are better/more accommodating to different individual needs.

Strategies suggested by Free State organisations:

- Understanding of your partners’ roles, resources they have and their capacity to integrate
- Establish coordinating structures which could implement a multi-sectoral approach
- Skills training and certification for the volunteer cadre within organisations

*“Continuous in-service training for service providers to address the issue of new trends in HIV, AIDS, and TB and new or proposed responses and targets.”*

- Care for the caregiver programmes (for debriefing)
- Where possible, there should be improvement of remuneration of skilled professionals within the sector
- Continuous mentoring, monitoring and evaluation of organisations.

## ACKNOWLEDGEMENTS

The team at NACOSA were most grateful for the participation at the 2015 AGM of Dithuso Monare, who delivered a keynote address on multisectoral working and Dr Pren Naidoo who delivered an address on the TB response in South Africa and introduced and facilitated the consultative forum. Both provided much food for thought and discussion during the consultative forum.

We also thank our chairperson, board and staff members, particularly those who facilitated discussion groups. Most importantly, NACOSA would like to thank the people from the organisations who participated so meaningfully in the discussions.

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### **NACOSA – Networking HIV/AIDS Community of South Africa**

t. 021 552 0804 | f. 021 552 7742 | e. [info@nacosa.org.za](mailto:info@nacosa.org.za)

NPO 017-145 | PBO 18/11/13/1602 | VAT 484 024 0990

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