LESOTHO CIVIL SOCIETY ORGANIZATIONS' HIV AND TB PRIORITY CHARTER FOR CHILDREN AND ADOLESCENTS

A Road Map to Engage with the Government of Lesotho and Other Organizations to Improve the Response to TB And HIV

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Makopano Letsatsi, 2019

NATIONAL AIDS COMMISSION

FOREWORD

In Lesotho, as in many other countries, civil society organizations (CSOs) have a potential role to play in translating the needs of people that they serve for policymakers' attention, creating opportunities for improved implementation of policy, and transferring information to marginalized and underserved populations. The CSOs further have the potential to play a critical role in advocacy and service delivery for the overall success of the national response to HIV and TB. So far, efforts to advocate for HIV and AIDS and TB in Lesotho have been challenged by a fragmented approach where each organization has been working in isolation limited synergising efforts toward a HIV and AIDS and TB response. It is against this background that the National AIDS Commission (NAC) with support from the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), found it imperative to support the development of this CSOs' priority charter. It is envisaged that through this charter, the CSOs can foster strategic partnerships to advocate for national issues related to HIV and AIDS and TB with one voice. This partnership is critical to any successful advocacy efforts, since unity is power.

Therefore, this charter shall serve as the culmination of CSOs' national coordinated efforts to advocate for HIV and TB issues for children and adolescents. One of the most drastic inequalities in the HIV response is the failure to achieve HIV and TB targets, especially those related to children and adolescents. Despite Lesotho's achievement of the 90-90-90 targets in its HIV response, the country is still behind on meeting HIV and TB targets among children and adolescents. Thus, this priority charter is designed to guide the advocacy journey to achieve equality in the country's HIV and TB response. It shall further guide the CSOs to ensure that the country closes the gaps between pediatric HIV targets and achievements in the HIV response, leaving no child or adolescent behind. Hence, Lesotho shall reach and provide access to HIV and TB care, treatment, and prevention to all—including children and adolescents.

It is crucial to note that both National Strategic Plans for HIV and TB allude to attaining the 95-95-95 targets by 2030. Program Result 2 of the National HIV and AIDS Strategic Plan (2018/2019–2022/2023) addresses interventions related to the elimination of mother-to-child transmission and ensuring that 95% of children living with HIV be on treatment by 2023. Program Result 1, Result Area 1.6 addresses interventions based on HIV prevention among adolescent girls and young women and their partners. Thus, the advocacy issues articulated in this charter shall guide programming to achieve the set national and global targets, with special attention to those of children and adolescents.

I, therefore, invite and urge all stakeholders to adopt and implement the guiding principles and priorities discussed in this charter. Let us demonstrate the same commitment shown during the development of this charter toward its implementation.

Mrs. Mamello Letsie
National AIDS Commission Acting Chief Executive

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We appreciate the support provided by

Elizabeth Glaser
Pediatric AIDS Foundation
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CONTENTS

ACRONYMS AND ABBREVIATIONS

ART	antiretroviral therapy
COVID-19	coronavirus disease of 2019
CSO	civil society organization
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
NGO	nongovernmental organization
NSP	National Strategic Plan
PEPFAR	U.S. Presidents Emergency Plan for AIDS Relief
PMTCT	prevention of mother-to-child transmission
PR	Priority Result
SGBV	sexual and gender-based violence
SRHR	sexual and reproductive health and rights
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations International Children's Emergency Fund
USAID	United States Agency for International Development
VAC	violence against children
VHW	village health worker
VMMC	Voluntary Medical Male Circumcision
WHO	World Health Organization

DEFINITIONS OF TERMS

ADOLESCENCE
The decade of life from 10 to 19 years of age, characterized by rapid physical, cognitive, and social changes that include sexual and reproductive maturity. It is an intermediate stage between childhood and adulthood.

ADVOCACY FRAMEWORK
A set of concepts that are used to guide planning toward processes for supporting a particular cause.

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)
A life-threatening condition representing the late clinical stage of an infection caused by HIV.

CHILDREN
Young humans between the developmental stages of infancy and puberty, between the ages of 0 and 10 years old.

CIVIL SOCIETY ORGANIZATION NONPROFIT
Voluntary entities formed by people in the social sphere that are separate from the government or state and the market. CSOs represent a wide range of interests and ties. They can include community-based organizations as well as nongovernmental organizations (NGOs).

HUMAN IMMUNODEFICIENCY VIRUS (HIV)
A microorganism that causes progressive damage to the immune system of an infected individual.

PRIORITY CHARTER
A written instrument outlining the most important strategic activities to be implemented by CSOs in response to TB and HIV among children and adolescents.

TUBERCULOSIS (TB)
An infectious disease caused by mycobacterium tuberculosis, mainly affecting the lungs but can affect any other organs or tissues and may manifest with cough, fever, listlessness, vague chest pains, night sweats, haemoptysis, purulent secretions, hoarseness, and debilitating weight loss.

TB/HIV COINFECTION
When a person is living with HIV and is also infected with TB.

BACKGROUND

Despite Lesotho's achievement of 90-90-90 targets at 90-97-92,[1] the country still lags in meeting TB and HIV targets among children and adolescents. It is estimated that about 13,000 children from ages 0 to 14 years old and 306,000 adults above 15 years of age are currently living with HIV in Lesotho.[2] TB case incidence is 654 per 100,000 people,[3] while HIV prevalence is 22.7%.[1] HIV and TB coinfection continues to pose challenges of adherence to both antitubercular medication and antiretroviral therapy (ART). ART coverage among adolescents and young people remains low, while viral load suppression among children is sub-standard.[4] For instance, in EGPAF-supported sites in the eight districts of Lesotho, viral load suppression among children below 1 year old and below 5 years old was 69% and 76% respectively, while for the age group above 15 years old it was 97%.[5] The risk of progression to TB disease is higher if infection occurs before adolescence, in the very young (0-4 years old), and in those who are immunocompromised.[6] Additionally, extrapulmonary TB is more prevalent in children, young adults, and in cases of HIV-associated TB. Therefore, it remains imperative to accord children and adolescents special consideration owing to their cultural, social, and economic and biological vulnerability.

AIM OF THIS CHARTER

The overall goal of this priority charter is to identify existing gaps in TB and HIV screening and management among children and adolescents in Lesotho. The objective is for CSOs to advocate for resources to enhance the delivery of programs targeting TB and HIV among children and adolescents. This charter will guide coordination, fund mobilization, ensure effective program implementation, and assist CSOs to speak with one voice using evidence-based gaps.

METHODOLOGY

An informative desk review of literature was initially conducted to understand the context in which CSOs were providing TB and HIV services among children and adolescents in Lesotho. This was followed by a baseline assessment to identify gaps in the provision of TB and HIV services among children and adolescents. During this process, a framework on which the priorities charter would be founded was also developed. Data was collected using three questionnaires. Questionnaire 1 elicited information on the interventions on TB and HIV among children and adolescents. Questionnaire 2 elicited information on advocacy activities undertaken by CSOs. Questionnaire 3 elicited information on the support provided by other key stakeholders such as government ministries and international organizations. Results of the baseline assessment were presented to stakeholders at a virtual participatory dialogue meeting during which they also identified priority strategies to be included in the charter. Finally, the charter document was validated and adopted at another virtual participatory dialogue meeting held in July 2021.

TARGET POPULATION

The target population includes children, caregivers for children and adolescents, and adolescents.

GUIDING PRINCIPLES

This charter is founded on the following principles:

PARTICIPATORY STRATEGIC PLANNING

As a civil society in Lesotho, we shall involve in strategic planning the communities we serve, at local, district, national, regional, and international levels. This shall build a strong, independent, and self-directed civil society that has public accountability and is harmonized to engage at local, district, national, regional, and international levels in influencing effective and clear TB and HIV interventions for children and adolescents. Strategic planning at the local and district level will be made through both the district AIDS committees for non-clinical interventions and the District Health Management Team (DHMT) for clinical interventions.

EQUITABLE FUNDING

We commit to equitable funding of programs that we deliver to ensure the inclusion of marginalized and vulnerable groups, including those affected by gender inequality, sexual and gender-based violence (SGBV), substance abuse, and inadequate nutrition. As such, inclusive representation from community-led, local, regional, and international organizations should improve health systems, strengthening initiatives directed toward children and adolescents.

UNIVERSAL, ACCESSIBLE, EQUITABLE HEALTH CARE SERVICES

We pledge to the provision of health care services that are equitable and accessible, and that universally address the health needs of children and adolescents. Through quality programs, we also commit to uphold human rights and serve populations that are marginalized and vulnerable, including orphans and vulnerable children, the disabled, and substance users, as well as to involve the communities in which they reside.

SUPPORTIVE CAPACITY BUILDING

We commit to partake in supportive capacity building activities to improve our performance in program delivery. As we respond to TB and HIV among children and adolescents, we shall further enhance our performance and avoid duplication of efforts by providing and/or participating in training on governance, leadership, management, project management, advocacy, communication, fundraising, universal health coverage, health systems strengthening, coordination and collaboration, monitoring and evaluation, and TB andHIV related to ART optimization, TB treatment especially for children and TB Preventative Therapy initiation for children 0-14 years.

PRIORITIES

To address the existing TB and HIV gaps i.e. poor TB case identification in children, high HIV incidence among adolescents and gender based violence, CSOs agreed on the following priorities that need to be addressed among children and adolescents:

PRIORITY AREA 1: INTEGRATED TB/HIV SERVICES

We have realized that CSOs are not all implementing both TB and HIV services within the communities served and that all our activities are linked to the strategic program priorities. At the same time, some CSOs implement health care facility–based interventions, while others only provide community-based interventions. Additionally, services provided are in chosen health care facilities or communities and are distributed disproportionately within the 10 districts of the country. We believe that the provision of integrated services in the programs that we provide shall bridge the gaps in TB and HIV case identification, detection, treatment, and management among children and adolescents. This shall minimize the negative effects of TB on the course of HIV and interrupt the transmission of TB to inhabitants of communities.[7]

STRATEGIES FOR ACTION

1.1 IMPROVE TB/HIV CASE FINDING AND DETECTION

National Strategic Plan (NSP) Link: ***HIV NSP Priority Result (PR) 7****: Health System is people-centred & sustainability integrates HIV, TB, and other diseases;* ***NSP PR 3****: Test & Treat cascade fast-tracked to attain 95-95-95 targets by 2023;* ***TB Policy PR 5.1****: All persons (regardless of HIV status) with clinical features suggestive of pulmonary tuberculosis must submit sputum for diagnostic sputum smear microscopy:* ***TB Policy PR 9.2.1****: TB/HIV programmes must ensure joint planning, coordination, and monitoring and evaluation system.*

CSOs acknowledge that the integration of TB/HIV services beyond health care facility–levels remains crucial not only for the early identification of cases but for their immediate linkage to care. This also has the positive potential to identify clients lost to follow-up care and possibilities of coinfections. Immediate linkages to care from a community perspective will also improve treatment support and care and ensure uninterrupted treatment. This can be achieved through the following interventions: community awareness and demand creation on TB services such as screening and HIV testing; index testing and partner notification; provider-initiated testing and counselling; HIV self-testing; pediatric HIV case finding; TB screening and contact tracing; presumptive TB testing for outpatients and inpatients or during integrated outreach activities ; village health worker (VHW) treatment support; and linkage to care. These can be rolled out not only in health care facilities, but in primary, secondary, and high schools, higher education institutions, and in villages where the clients live.

EXPECTED OUTCOMES

i. Improved health and wellness among children and adolescents
ii. Early TB/HIV diagnosis and linkage to treatment
iii. Increase in TB/HIV knowledge among target populations
iv. Increased uptake of TB/HIV testing services

1.2 INCREASE ACCESS TO TB/HIV TREATMENT AND MANAGEMENT

NSP Link: ***HIV NSP PR 2:*** *Mother-to-Child transmission elimination & 95% of Children living with HIV are on treatment by 2023;* ***NSP PR 3****: Test & Treat cascade fast-tracked to attain 95-95-95 targets by 2023;* ***TB policy PR 7.1:*** *TB treatment shall aim to cure patients of active TB, prevent death from TB or its complications, decrease transmission of the disease to others, and to prevent the development of drug resistance.*

We acknowledge that social drivers of TB/HIV continue to affect treatment adherence. Children and adolescents remain vulnerable to TB and HIV owing to biological vulnerabilities, social disparities, gender inequalities, and SGBV. Furthermore, access remains low due to limited adolescent-friendly services and care that is dependent on children's caregivers. Even after knowing their TB/HIV status, stigma, discrimination, and victimization continue to hinder effective treatment uptake, not only in families but in communities and among peers as well. In health care facilities, increasing access to treatment shall take place through the following: prevention of mother-to-child transmission (PMTCT); optimized ART for children and adolescents; viral load clinics; pre-exposure prophylaxis; post-exposure prophylaxis; TB preventive therapy; TB treatment; VHW treatment support; and retention of care using advanced technologies.

EXPECTED OUTCOMES

i. Increase in coverage among children and adolescents for TB preventive therapy and TB/HIV treatment
ii. Reduced TB/HIV morbidity and mortality among children and adolescents
iii. Reduction in number of TB/HIV clients lost to follow up
iv. Attainment of HIV viral suppression (<50 copies/mL)
v. Improved health and wellness among children and adolescents

PRIORITY AREA 2: PREVENTION OF NEW TB/HIV INFECTIONS

Various literature reports a high incidence of HIV among adolescents owing to early sexual debut among girls and boys;[8] discordancy, gender-based violence, and gender inequalities among adolescent girls and young women;[9] intergenerational sexual relationships between girls and older men that create challenges in negotiating for condom use, safer sex, and power dynamics; and low levels of knowledge that hinder behaviour change and demand creation on voluntary medical male circumcision VMMC, condoms, and test-and-treat services.[10]

SGBV drives the HIV epidemic among adolescent girls and young women, with an HIV prevalence 58% higher among those who report having been forced to have sex than among their counterparts who have not.[11] Violence against children (VAC) can be physical, mental, or sexual; can occur among peers, within marriage, in family units, or schools; and can be inflicted by adults (including intimate partners).[12] The comorbidity of TB and HIV continues to be a big challenge in managing the two diseases. TB is the leading cause of death among people with HIV, while HIV increases the risk of TB infection.

STRATEGIES FOR ACTION

2.1 REDUCE TB/HIV INCIDENCE AND PREVALENCE

NSP link: HIV NSP PR 1: *90% of people aged 15 and over at risk of HIV have accessed combination HIV prevention by 2023;* **TB policy PR 4.2:** *HIV infected people (including children) should be screened for TB; Children who are in close contact with an active TB case, especially those under the age of five should be screened for TB.*

A reduction in the incidence and prevalence of TB and HIV among children and adolescents will reduce the general disease burden within the country. This will not only improve the health outcomes of children and adolescents but their socioeconomic endeavors and life expectancies as well. This can be achieved through social change and communication; economic strengthening activities for adolescents; comprehensive services on sexual and reproductive health and rights (SRHR) for adolescents; comprehensive sexuality education; empowerment of CSOs on TB/HIV and SRHR, and support on appropriate information, education and communication by the health education unit of the Ministry of Health; TB/HIV treatment literacy through mass media platforms; pre-exposure prophylaxis; post-exposure prophylaxis; TB preventive therapy; condom promotion; cervical cancer screening; and voluntary medical male circumcision.

EXPECTED OUTCOMES

i. Increased access to SRHR services by adolescents
ii. Reduced self-reported stigma, discrimination, and victimization
iii. Improved correct and consistent condom use
iv. Increased uptake of TB preventive therapy
v. Increased uptake of TB/HIV testing services

2.2 REDUCE TB/HIV INCIDENCE DUE TO SEXUAL AND GENDER-BASED VIOLENCE (SGBV) AND VIOLENCE AGAINST CHILDREN (VAC)

NSP Link: ***HIV NSP PR 4****: Gender & Human Rights related Barriers to service delivery, accessibility & utilization removed by 2023;* ***TB policy PR 4.2****: HIV infected people (including children) should be screened for TB; Children who are in close contact with an active TB case, especially those under the age of five should be screened for TB.*

Addressing SGBV and VAC remains a key intervention to improve the health outcomes of children and adolescents in Lesotho. Victims and survivors of SGBV and VAC are at risk of sexually transmitted infections (including HIV), unwanted pregnancies, and unsafe

abortions. Psychological effects that can result are depression, social isolation, stress, and failure to have intimate relationships in the future. We believe that targeting the social arena where the victims live will assist in curbing such behavior from culprits and further protect children and adolescents. Interventions include the following: pre-exposure prophylaxis; post-exposure prophylaxis; TB preventive therapy; community awareness campaigns on forms of SGBV, VAC, and early childhood marriages; community awareness campaigns on human rights, gender equality, stigma, discrimination, and victimization; capacity building for CSOs and other stakeholders on reporting and referral of victims and survivors of SGBV and VAC; comprehensive SRHR services for adolescents; comprehensive sexuality education; and engagement with policymakers to address structural barriers to TB/HIV among children and adolescents.

EXPECTED OUTCOMES

i. Increased community knowledge on SGBV, VAC, human rights, and gender equality
ii. Reduced self-reported stigma, victimization, and discrimination among children and adolescents
iii. Reduced TB/HIV incidence due to SGBV and VAC

2.3 DECREASE SOCIAL DISPARITIES AND VULNERABILITY TO TB/HIV

NSP Link*: **HIV NSP PR 5**: Strengthened national social & child protection systems to ensure 75% of PLHIV, & those at risk of & affected by HIV benefit from HIV sensitive social protection by 2023;* ***TB policy PR 3.2.1****: Strengthen and sustain advocacy, communication, and social mobilization, involving private and voluntary health care providers, economic analysis, and financial planning, and operational research.*

Social disparities and vulnerability to TB/HIV continue to impede efforts in managing TB and HIV in Lesotho. Adolescent girls have been reported to engage in sexual encounters with men ten years their senior or older in an attempt to improve their economic status. TB and HIV have also caused many children to be orphans after the death of their parents, which adds to their vulnerability in society. CSOs are well situated to assist individuals, families, and communities to fight social disparities that drive TB/HIV, using community rights and gender approaches. They have greater access to populations that are vulnerable to TB/HIV, including orphans and vulnerable children. Interventions to reduce public inequities include management of orphans and vulnerable children; provision of friendly services (including PMTCT, pre-exposure prophylaxis, and post-exposure prophylaxis); social behavior change and communication; advocacy at the peer level; peer and social cluster clubs; establishment of community awareness groups; strengthening of family support systems; provision of adolescent-friendly services at primary, secondary, high schools, and higher education institutions; and enhancing linkage and retention of care.

EXPECTED OUTCOMES

i. Increased knowledge on TB/HIV among caregivers, children, and adolescents
ii. Reduced self-reported stigma, discrimination, and victimization

iii. Increased healthy lifestyles and wellness for children and adolescents

iv. Reduced TB/HIV incidence among target populations, including OVC

v. Improved coordination of TB and HIV interventions at the community level

vi. Improved monitoring and reporting of TB and HIV interventions by CSOs

PRIORITY AREA 3:
REINFORCEMENT OF COMMUNITY SYSTEMS

We acknowledge that as CSOs working in Lesotho, our work has not always been integrated, resulting in duplications of effort due to poor coordination. The involvement of communities in the fight against TB and HIV has not been adequate due to program time constraints and the COVID-19 pandemic. Improving community systems will enhance social wealth, cohesion, and reduce segregation. Increasing allocation of resources in program services will enhance activities toward improving community systems and their linkage to health facilities. This shall work to reduce the burden on health care facilities and improve monitoring and evaluation by communities.

STRATEGIES FOR ACTION

3.1 IMPROVE COLLABORATION AND COORDINATION AMONG CSOS

NSP Link: ***HIV NSP PR 6****: At least 40% of the TB/HIV response is community-led and sustainable by 2023;* ***TB policy PR 3.2.1****: Strengthen and sustain advocacy, communication, and social mobilization, involving private and voluntary health care providers, economic analysis, and financial planning, and operational research;* ***TB Policy PR 9.2.1****: TB/HIV programmes must ensure joint planning, coordination, and monitoring and evaluation system.*

CSOs need regular support to improve their footprint in the fight against TB/HIV. Notably, more engagement with the National AIDS Commission, Ministry of Health, Ministry of Education and Training, and other government entities will enhance their buy-in to the priority charter. The capacity to strengthen existing structures can also enhance the involvement of communities in which CSOs work. This can be achieved through community rights and gender initiatives that include the following activities: capacity building of CSOs on TB/HIV services; strengthening of community-based monitoring and evaluation; strengthening links between communities and health care facilities; retention of care and support; adherence of support using advanced technologies; establishment of community awareness groups on TB/HIV; using the priority charter to inform the gap analysis during proposal-writing processes in platforms such as the Lesotho Country Coordinating Mechanism, as well as a reference document in engaging in relevant technical working groups.

EXPECTED OUTCOMES

i. Increased community involvement in TB/HIV

ii. Increased community knowledge on TB/HIV

iii. Improved coordination and collaboration between CSOs and health facilities

iv. Increased advocacy on TB/HIV, especially for children and adolescents

v. Increased representation from CSOs in relevant technical working groups

vi. Increased capacity of CSOs on TB and HIV programs

vii. Increased engagement with Health Education Unit of the Ministry of Health and Learner Care and Welfare Support Unit of the Ministry of Education and Training

TIMELINES

This charter is linked to the National TB Policy and Manual (2016) and National HIV Strategic Plan (2018/19–2022/23) in Lesotho and will be reviewed every 2 years.

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