

FOR MORE INFORMATION

 +234(0)816-431-7505

 anayd2017@gmail.com
contact@anayd.org

 No, 39A Gwari Avenue GRA,
Barnawa, Kaduna State

 www.anayd.org

ADOLESCENT AND YOUTH

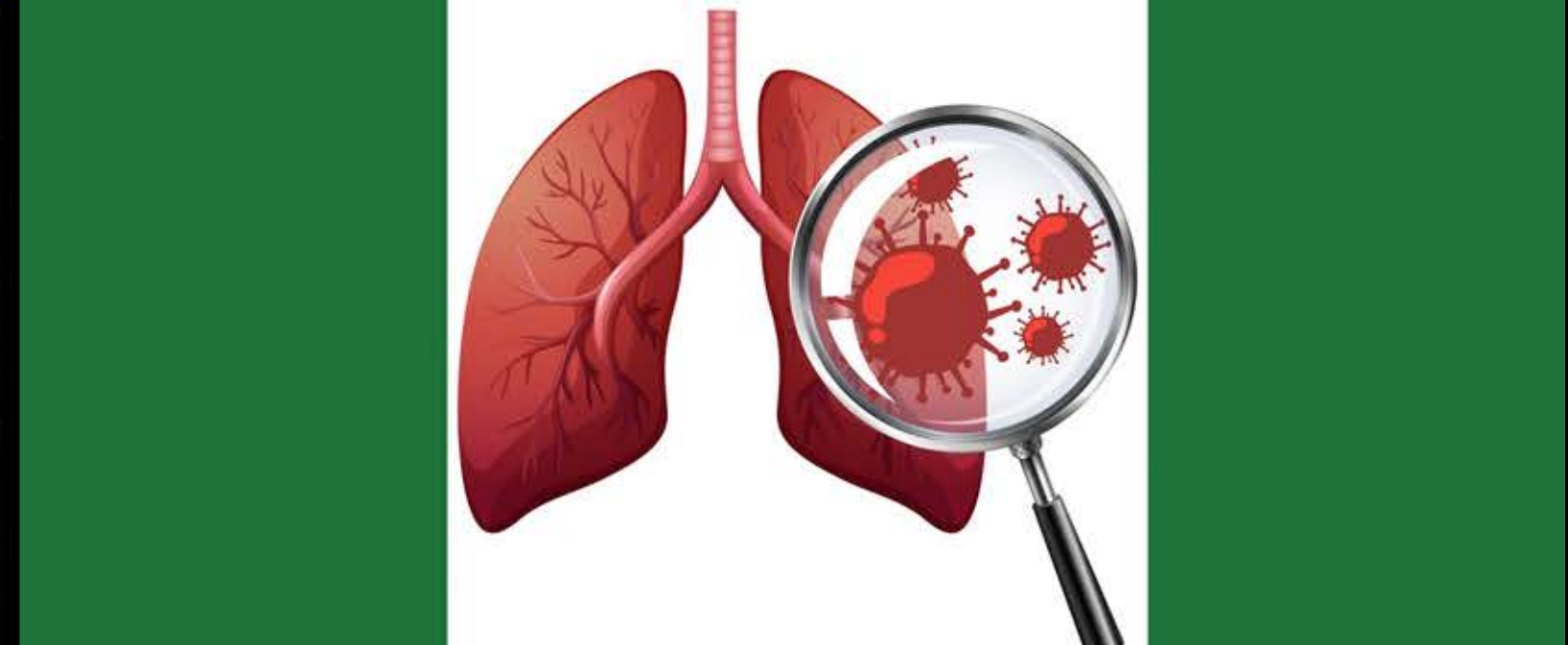
TUBERCULOSIS POLICY AND ADVOCACY
BRIEF

With support from
THE GLOBAL FUND
Community Engagement Strategic Initiative



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BACKGROUND and RATIONALE

Tuberculosis (TB) remains a significant global health concern, ranking as the second leading cause of death from infectious diseases worldwide (1). Globally, around 10 million individuals develop active TB, with an estimated 1.8 million of these being youth aged 15 to 24 years (2,3). In 2022, Nigeria's estimated incidence rate was 219 cases of TB per 100,000 population, translating to approximately 467,000 individuals with TB (2,4), positioning Nigeria among the ten countries with the highest TB rates globally (2). TB is a major public health challenge, particularly among young people in Nigeria (5). It not only threatens adolescents and youth (AY) immediate health but also has long-term socio-economic implications, affecting education, employment, and future productivity.

The COVID-19 pandemic exacerbated the challenges faced by Nigeria in combating TB, reversing years of progress in the fight against it (6). Studies have shown that AY has been disproportionately affected by the impact of COVID-19 on TB care (6, p.1, 7). The pandemic also compounded the existing stigma surrounding TB, with AY potentially being more reluctant to seek care due to fears of contracting COVID-19 (8). Fears and stigma, combined with the disruptions in TB services, prompted AY to conceal their condition often delaying seeking diagnosis until the disease had progressed (9).

This brief identifies critical gaps in young people's engagement opportunities within Global Fund-supported TB grants. The current Grant Cycle 7 TB grant (January 2024 – December 2026) is implemented by the National Tuberculosis, Leprosy & Buruli Ulcer Control Programme (NTBLCP) as the Principal Recipient and amounts to \$US 122,390,772(10). The brief highlights barriers AY faces in current TB programming, as identified by young people themselves. It also proposes practical steps to strengthen AY's meaningful engagement in the processes related to the Global Fund grant in Nigeria and their involvement in interventions to address TB, drug-resistant TB (DR-TB), and multidrug-resistant TB (MDR-TB).

TARGET AUDIENCE

This policy brief is intended to support the work of adolescent and youth-led organizations that represent or engage with people affected by TB, DR-TB, MDR-TB, and young key populations, affected by TB. The brief is a valuable resource for the Country Coordinating Mechanism (CCM), the NTBLCP, key TB stakeholders, including the Stop TB Partnership Nigeria, and funding organizations.



GLOBAL AY ENGAGEMENT PRINCIPLES AND NATIONAL TB COMMITMENTS

CONSENSUS STATEMENT ON MEANINGFUL ADOLESCENT AND YOUTH ENGAGEMENT

The Global Consensus Statement, We Matter Value Us, and the Youth Next-Level Guideline on Meaningful Adolescent and Youth Engagement (MAYE) provide a reference framework for effectively involving AY in health and development initiatives. In August 2020, over 200 global health and development organizations and leaders committed to valuing and integrating AY voices in policy and program design, investing in AY leadership development, promoting collaboration with AY, and upholding the participation rights of this population in matters affecting their lives (11).

MAYE emphasizes inclusive, respectful partnerships between AY and adults. The statement defines meaningful engagement as integrating AY's ideas, perspectives, skills, and strengths into the design, implementation, monitoring, and evaluation of policies, programs, and initiatives that impact adolescents and youths and their communities (11,12,13).

NATIONAL STRATEGIC PLAN: HIGHLIGHTS FOR TB IN AY

Nigeria's 2021-2025 National Strategic Plan (NSP) for TB commits to strengthening TB services for AY by improving access to TB diagnosis and treatment, enhancing community-based case detection, and ensuring family-centered care. The NSP also aims to address social determinants of health that impact TB outcomes among AY and to integrate TB services with other health programs focused on AY's health and development (14). By prioritizing AY, Nigeria strives to reduce TB incidence and improve outcomes for this vulnerable population.

METHOD

This policy brief is based on two sources: a desk review of the existing TB and AY-related documents in Nigeria, and insights from ten key informants, representing the Stop TB Partnership Nigeria, the African Coalition on TB Nigeria (ACT-Nigeria), and TB People Nigeria. In addition, this brief's credibility, relevance, and accuracy were validated by over 100 AYs and Global Fund-supported program sub-recipients present at two-day consultation workshops in Anambra, Kano, Rivers, and Benue States of Nigeria.

BARRIERS TO ENGAGEMENT IN GLOBAL FUND PROCESSES AND TB PROGRAMMING

Key informant interviews indicate that young people have limited awareness of the Global Fund structures, processes, and initiatives. These knowledge gaps hinder their meaningful engagement in Nigeria's Global Fund-related processes.

Respondents also highlighted that improvements were needed in promoting direct communication and creating feedback loops between youth representatives on the CCM and young people affected by TB, as well as between the TB constituency representatives on the CCM and AY. The current lack of these mechanisms creates an information gap regarding integrating youth-relevant TB issues into CCM discussions, deliberations, and decision-making processes.

Regarding opportunities for youth organizations to implement TB activities, respondents emphasize that the stringent criteria required to become a (sub-)sub-recipient of the Global Fund grant often deter youth-led organizations from applying, effectively excluding them from implementation roles.

The application procedures are perceived as complex, demanding substantial organizational experience, technical know-how, and proof of financial capacity that many youth-led organizations do not yet have. During consultation workshops, AYs pointed out that a lack of awareness at grassroots and state levels about the opportunities to engage hinders their participation in Global Fund and National TB programming. Additionally, limited financial and technical resources further hinder their active participation in these processes.



BARRIERS TO TB SERVICES UPTAKE

Despite the availability of free facility-based TB services across Nigeria, many AY encounter a myriad of barriers that prevent them from accessing timely diagnosis and effective treatment. These obstacles are deeply rooted in socioeconomic factors, stigma, and a healthcare system that often overlooks the unique needs of AY. This section draws on key informant interviews and personal narratives from participants to reveal a stark reality for many AY affected by TB.

During the key informant interviews conducted with AY, a key informant recounts their struggle with TB, recalling how the news of their diagnosis was delivered coldly, devoid of compassion. “You have TB,” the doctor stated bluntly, sending them to another room for further instructions. This lack of empathy left them feeling abandoned at a time when they needed support the most. The absence of youth-friendly spaces and support groups within healthcare facilities only exacerbated their sense of isolation, highlighting how TB services often fail to address the specific needs of young people. Even in regions where services are available, the quality of care often fails to meet the unique needs of young populations.

Compounding the above challenges is the pervasive stigma surrounding TB, which can lead to social exclusion. An AY described how having TB resulted in a profound sense of alienation. “During treatment, I felt like a pariah—no one wanted to associate with me,” they shared, reflecting on the toll this discrimination took on their mental health. The fear of ostracization loomed, creating a barrier that kept many AYs from seeking the service they desperately needed. A key informant from Benue State articulates that in a significant number of AY who get TB again, it can be traced back to their living environments, often characterized by overcrowded spaces and economic vulnerability. These conditions in impoverished urban settlements, coupled with informal employment, perpetuate a vicious cycle of health issues.

Additionally, at the training and consultation workshop in Kano State, a key informant stresses that concerns about potential side effects of TB medication, continue to serve as a significant barrier.

In their statement, “some AY may even prefer to endure the consequences of TB rather than face the possibility of experiencing side effects from the medications”. These are clear indicators of the need for targeted educational and awareness-raising initiatives to empower AY with knowledge and skills to proactively engage with the healthcare system.

Similarly, key informants emphasized that the financial burden of diagnosis and treatment remains a significant obstacle. Despite the lack of direct costs for TB services, associated expenses — such as transportation and lost income from missed work — add to the challenges faced by AY. Lastly, key informants in Rivers State shared that prolonged waiting time at health facilities, concerns about confidentiality, service providers’ attitudes, and the

absence of rapid TB diagnosis testing kits contribute to delayed diagnosis and suboptimal treatment outcomes among AY.

While community, rights, and gender assessments (15,16, 17) have shed light on the challenges in accessing TB diagnosis and care faced by vulnerable communities in general, the specific impact of legal and gender barriers on AY and young key populations is not well-documented. A WHO assessment of barriers to the utilization of general health services by disadvantaged adolescents has found significant gaps in the accessibility, availability, and quality of TB services, particularly in remote and hard-to-reach areas (18).

Barriers to TB service uptake by young people highlight the need for economic enablers, improving the quality of age-specific care, targeted awareness-raising, and addressing misconceptions, for AY to more proactively engage with the healthcare system.



YOUTH ENGAGEMENT PLAN

During the four training and consultation workshops across different states, AY developed concrete steps to enhance youth engagement. The Youth Engagement Plan (2024-2026) is centered around four main objectives:

1. Strengthening youth engagement on TB issues at the CCM;
2. Increasing youth awareness about TB and generating demand for available TB services;
3. Intensifying youth engagement in Community-Led Monitoring (CLM) and potentially other GC7 interventions;
4. Advocating for GC7 youth-led implementation of TB activities, and preparing for engagement in GC8.

The detailed plan ([Youth Engagement Plan](#)) contains key activities in support of the four objectives and proposes concrete timelines, targets, responsible parties, and monitoring mechanisms. The Youth Engagement Plan is aligned with and will be further supported by the implementation of the recommendations below.



RECOMMENDATIONS

The recommendations below address two critical areas: enhancing the meaningful engagement of AY in Global Fund and TB-related processes, and enhancing TB services uptake among this crucial demographic. Each recommendation identifies key stakeholders for implementation and is evaluated on Impact and Feasibility (High or Medium), focusing solely on urgent and achievable initiatives.

RECOMMENDATIONS TO ENHANCE THE MEANINGFUL ENGAGEMENT OF YOUNG PEOPLE IN THE GLOBAL FUND AND TB-RELATED PROCESSES

1. Resourcing and Implementing Youth Engagement Plan:

Allocate funding, carry out and monitor the implementation of the Youth Engagement Plan (2024-2026).

2. Promoting Regular Consultations with AY:

Organize regular data-driven and evidence-based consultations with AY, throughout the Global Fund grant cycle: from TB funding request development to close-out, and consider their inputs when making reprogramming decisions.

Stakeholders: Youth Constituency representatives, TB Constituency representatives on the CCM, and the CCM Secretariat.

Impact and Feasibility: High Impact, High Feasibility

3. Establishing a Youth Advisory Committee:

Create a youth advisory committee at the CCM as part of strengthening CCM feedback mechanisms and to serve as a platform for AY to voice their concerns, share their experiences, and influence policies that impact their health and well-being.

Stakeholders: CCM and CCM Secretariat, Youth representatives, and TB constituency representatives.

Impact and Feasibility: High Impact, Medium Feasibility.

4. Strengthening the Capacity of AY-led Organizations:

Develop a comprehensive training program for AY and their organizations to equip them with knowledge and skills in

- (1) TB response;
- (2) community-led research, CLM, advocacy, policy formulation, and grant proposal writing;

- (3) Global Fund-related areas, such as Global Fund policies, funding cycles, and in-country architecture and processes.

Stakeholders: NTBLCP, TB Network, and ANAYD.

Impact and Feasibility: High Impact, High Feasibility.

- 5. **Promoting Peer Education Initiatives:** Facilitate peer education initiatives where trained young professionals and advocates can share their knowledge and skills with their peers, for instance, at an annual Youth TB summit.

Stakeholders: NTBLCP, TB Network, and ANAYD

Impact and Feasibility: High Impact, High Feasibility

- 6. **Establishing Mentorship Programs:** Establish mentorship programs to develop AY skills in leadership, management, and organizational development, including governance, financial management, project management, administration, and volunteer engagement.

Stakeholders: ANAYD, and TB Network

Impact and Feasibility: High Impact, Medium Feasibility

- 7. **Fostering Partnerships between Youth-led organizations and other Professionals:** Facilitate partnerships between young people-led TB organizations, and organizations and professionals in other epidemic responses (HIV, malaria) to guide and support joint advocacy for young people's health and well-being.

Stakeholders: ANAYD, and TB Network

Impact and Feasibility: High Impact, Medium Feasibility

RECOMMENDATIONS TO IMPROVE TB SERVICES UPTAKE AMONG YOUNG PEOPLE

- 8. Investing in the implementation of the Human Rights and Gender Action Plan for Tuberculosis Care and Prevention in Nigeria 2021 – 2025 by the Ministry of Health (MoH), and NTBLCP will have a transformative impact on young people, particularly through the following interventions:

- a. Law Reform Proposal on Gender and Human Rights in the Context of TB;Stakeholders: NTBLCP, `Federal Ministry of Health (FMoH), Lawyer Alert, Youth-Led Human rights activists, Youth TB partners, and other multi-sectoral stakeholders.

Impact and Feasibility: High impact, High Feasibility.

- b. Enhancing judiciary and the legal community's awareness of a human rights-based, gender-transformative TB response and their role in the response;Stakeholders: NTBLCP and mapped youth-led organizations working on human rights and gender issues.

Impact, and Feasibility: High Impact, High Feasibility.

- c. Developing Social and Behavioral Change Communication materials for stigma reduction and discrimination in TB; Stakeholders: NTBLCP in collaboration with FMOH, mapped youth-led organizations working on human rights and gender issues, and other multi-sectoral stakeholders.
Impact and Feasibility: High Impact, High Feasibility.

9. Engaging TB Survivors as Champions:

Train and empower TB survivors to demystify misconceptions about TB and serve as Counselors and Treatment supporters at the facility level and in all levels of programming.

Stakeholders: NTBLCP, in-state Sub Recipient, and Sub-Sub Recipient, and youth-led organizations.

Impact and Feasibility: High Impact, Medium Feasibility.

10. Utilizing Mobile Clinics and Community Health Workers:

Deploy mobile clinics and trained community health workers to deliver TB services directly to AY in underserved areas, effectively addressing geographical and social barriers to care.

Stakeholders: State Ministry of Health (MoH), NTBLCP, and State Tuberculosis Buruli and Leprosy Control Program (STBLCP)

Impact and Feasibility: High Impact, High Feasibility

11. Enhancing Patient Information on TB Medications:

Provide adequate information about TB medications' side effects, and what is done to mitigate side effects, as part of comprehensive patient information provided to young people who get diagnosed with TB.

Stakeholders: NTBLCP, Healthcare providers, grant implementers at the state level, and youth-led CBOs.

Impact and Feasibility: High Impact, High Feasibility.

12. Promoting Treatment Adherence in Marginalized Contexts:

Support treatment adherence among AY living in marginalized contexts and rural areas, by providing enablers such as nutritional support, and transportation reimbursements, and linking them up with self-help and income-generating activities during treatment.

Stakeholders: Sub Recipients and Sub-sub Recipients at the state level in collaboration with youth-led CBOs for integrated TB care.

Impact and Feasibility: High Impact, High Feasibility

13. Creating Youth Support Groups within Healthcare Facilities:

Establish youth support groups at healthcare facilities in the community settings where young people access TB services; engaging TB survivors- particularly AY TB champions as mentors to promote treatment completion among young people.

Stakeholders: NTBLCP, STBLCP, State MoH, Sub Recipients, and Sub-sub Recipients at the state level in collaboration with youth-led CBOs for sustainability.

Impact and Feasibility: High Impact, Medium Feasibility

14. Training Healthcare Staff on Youth-Centered Care:

Conduct comprehensive training for healthcare staff focused on reducing stigma, delivering clinically effective, non-discriminatory, and empathetic TB care, and addressing the unique biological, psychological, and emotional needs of AY accessing TB diagnosis and treatment.

Stakeholders: Federal and State MoH, NTBLCP, STBLCP, and youth-led CBOs

Impact and Feasibility: High Impact, High Feasibility

By implementing these recommendations, stakeholders can ensure that young people are effectively engaged in the Global Fund TB-related processes and that TB services are more accessible, inclusive, and responsive to young people's unique needs, ultimately leading to better health outcomes for this vulnerable population.



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