

# SMILE OVC program uses targeted approach to boost TB case-finding among vulnerable children

**Sustainable Mechanisms for Improving Livelihoods and Household Empowerment (SMILE)** is a five-year (April 2013–December 2018) cooperative agreement between Catholic Relief Services (CRS) U.S. Agency for International Development (USAID). CRS Nigeria leads the SMILE consortium which includes ActionAid Nigeria and Westat. SMILE is designed to improve the wellbeing of 500,000 orphans and vulnerable children (OVC) and 125,000 caregivers in Benue, Kogi, Edo, and Nasarawa states and the Federal Capital Territory, Abuja. Household economic strengthening, HIV and health services, child protection, psychosocial support, and education are some of the core services delivered to targeted priority populations. Nearly 50 local civil society organizations received sub-grants to strengthen their technical capacity and to deliver high-quality services to OVC and their caregivers through trained community volunteers.

## BACKGROUND

The World Health Organization (WHO) estimates that one million children (<15 years) currently suffer from tuberculosis (TB) worldwide, and more than 210,000 die each year.<sup>1</sup> Estimating the burden on children is difficult because younger children often present with nonspecific symptoms that mimic other childhood illnesses, and traditional diagnostics lack sensitivity. In 70–80% of cases, children develop the pulmonary form of TB, and although the source of infection is usually an adult with active TB in close contact with the child, it may take up to a year for children to exhibit symptoms. Up to half of children exposed to active TB will develop the latent form, which may progress to active during a subsequent, unrelated illness.<sup>2</sup>

Nigeria's children, especially those living in high-density, slum communities, are at high risk for contracting TB. Nigeria has the highest TB burden in Africa, with an estimated half-million new cases every year.<sup>3</sup> Notification rates are alarmingly low, with only 100,433 notified in 2016,<sup>4</sup> approximately 20% of actual cases. Of children under 5 who were in contact with a bacteriologically confirmed TB case in 2016, only 18% received preventive treatment.<sup>5</sup> Nigeria's Ministry of Health acknowledges that the algorithms and protocols for diagnosing and treating childhood TB are poorly understood by healthcare workers; contact-tracing activities are

chronically underfunded; new diagnostics are lacking; isoniazid preventive therapy (IPT) to prevent TB in exposed children is not widely used;<sup>6</sup> and pediatric formulations of TB drugs are often not available.<sup>7</sup>

Nigeria's HIV prevalence is 2.9%.<sup>8</sup> Since people living with HIV are highly susceptible to TB, its presence in the household further increases a child's risk of exposure to TB through a co-infected adult. The presence of active TB in children, as in adults, signals the need to rule out HIV infection. For children with TB and HIV co-infection, illness progression is likely to be rapid and fatal, thus early identification of both, as well as prompt treatment initiation and adherence, are crucial life-saving interventions.

## THE SMILE APPROACH

In 2016, leveraging the robust infrastructure and partnerships of a large, multi-sectoral orphans and vulnerable children (OVC) program, SMILE expanded its core mandate to include community childhood TB case-finding (CTBC) programming, with a focus on highly vulnerable children and their caregivers. Aligning closely with the National Tuberculosis Program (NTP), this initiative aimed to bolster existing efforts by improving NTP capacity and commitment to active case-finding (ACF) of childhood TB cases. As per a funding agreement with USAID, SMILE integrated CTBC activities into its

existing child-focused interventions in Benue state, aiming to identify presumptive pediatric TB cases from the program's targeted beneficiaries.

Working through its network of existing relationships, SMILE began building capacity in CTBC programming among government and civil society organization (CSO) partners. Training, mentorship, and field experience brought key players up-to-date, building proficiency among Ministry of Health's TB and leprosy supervisors (12) and disease surveillance and notification officers (12), and extending their reach through CSO staff and case managers (61) and community volunteers (CVs; 1,261). Simultaneously, SMILE's sensitizations and advocacy meetings brought community leaders, traditional rulers, and local government area (LGA) officials on board with its newly expanded mandate. SMILE rolled out its community- and household-level health promotion strategy to raise awareness about TB transmission, signs and symptoms, treatment, and prevention.

SMILE worked with the NTP to modify the existing screening tool for use with children, capturing the growth delays and failure to thrive that often characterize TB-infected children. SMILE also trained CVs and conducted TB screenings during routine community activities (maternal-child health clinics, immunization days, etc.), at schools, and during house-to-house campaigns. At home visits, CVs first inquired whether there was any known TB case in the household, then applied the NTP screening tool, asking child caregivers the following:

1. Has the child been coughing for two weeks or more?
2. Has the child been losing weight recently or not growing properly?
3. Has the child been having fever for a long period of time?
4. Has the child been having excessive night sweats?
5. Does the child have swellings on the neck?

When a "yes" response was generated to *any* of the screening questions, the child was considered "presumptive" and referred for follow-up at a health facility. CSO case managers facilitated immediate escorting for such cases as well as transporting sputum samples to facilities where rapid TB diagnosis and antibiotic sensitivity testing was available through GeneXpert. Project funds were used to pay for transport of children and caregivers. Escorted referrals ensured easy access to diagnostics and reduced turnaround times, which led to high referral completion rates and treatment initiation. Adult caregivers and household members were also screened and, if suspected of TB, encouraged to seek care. Case managers provided real-time support for

treatment initiation, which was key to uptake of services. SMILE's provision of escort and transportation was often sufficient to include any other family member with TB symptoms. CVs were trained to protect themselves by adhering to infection-control principles such as handwashing, minimizing exposure during transport of samples, protective airflow, and avoiding close contact with active TB cases. Individuals identified with presumptive TB were also tested for HIV, as per NTP protocol. Since HIV and TB services are not always co-located, some cases were referred to a second facility for HIV testing. SMILE ensured that linkages between service points were clear and provided escorting as required.

Wholehearted engagement of key influencers, such as religious and community leaders, traditional rulers, and local government authorities, was demonstrated through their explicit support of CTBC events, promoting the "TB anywhere is TB everywhere" campaign to reduce stigma, and wielding their authority with individual denialist or noncompliant households. Similarly, health facility staff welcomed SMILE's support in reaching some of Benue state's most disadvantaged and vulnerable households. SMILE worked with facility staff to streamline the progress of presumptive cases through diagnosis to successful treatment. They anticipated the burden of increasing case numbers and removed logistical barriers, including engaging private diagnostic service providers and prompting proactive requisitioning of adequate medications and diagnostic supplies.

Despite all these efforts, from October 2015 through September 2016, after screening 29,008 beneficiaries across its 17 LGAs, SMILE identified only 217 presumptive cases and confirmed only 19 cases of pediatric TB. **Reflecting on lower-than-expected yields and acknowledging the vast unmet need, SMILE responded with a bold new vision.** In collaboration with the NTP, SMILE narrowed its coverage area from 17 LGAs to 12, and honed in on 56 high-TB-burden slum communities. Reaching beyond its OVC beneficiary list, SMILE brought community-wide ACF to *all* children in those communities.

## RESULTS

The revised strategy had immediately gratifying results. The initial three-week exercise was implemented across the 56 communities, with a follow-up campaign six months later. Some of the communities were in hard-to-reach areas beyond SMILE's operational area, but staff were strongly motivated by the early higher yields. Targeted households, despite not benefiting from SMILE's core program, welcomed this life-saving initiative.

A total of 11,125 children were screened for TB between February and August 2017, with 2,553 presumptive TB

cases referred for diagnosis. A total of 1,767 children (69%) completed their referrals, with 466 children diagnosed with active TB (Table 1). *This represents a dramatic increase over performance* in the three preceding years (2014/79 cases, 2015/112 cases, 2016/116 cases), **illustrating the advantage of combining a robust ACF strategy with geographical targeting.** Unfortunately, a shortage of pediatric TB drugs and a health workers' strike delayed treatment initiation for many. Notwithstanding, 424 children commenced treatment and 316 successfully completed their six- to nine-month course by the end of June 2018.

The SMILE team was pleased by its **success in identifying new pediatric HIV cases.** WHO affirms the importance of HIV testing for *all* presumptive child TB cases.<sup>9</sup> Although SMILE's expanded mandate was aimed at detecting presumptive TB among children and ushering them through the diagnostic process, SMILE also mentored DOTS (directly observed treatment short-course) officers to ensure these cases were screened for HIV and referred for HIV testing and services (HTS).

Facility TB registers were used by SMILE staff to track progress through TB diagnostic and treatment services, and to gather information on the effect of TB screening as an entry point to HTS (Table 2). Adherence to established TB/HIV protocols and SMILE support brought nearly 60% (1,475) of children with TB symptoms to HIV testing. Children with confirmed TB illness were considered high priority for HTS, and of those, 87% of the referrals (404) were successfully completed. **Results revealed that 29 children were HIV positive, and 20 of them were co-infected with TB and HIV.** Getting these children treatment has saved their lives. SMILE data likely underestimates the actual results, as some families chose to use other facilities for HIV services, and the upkeep of TB registers is generally suboptimal.

## CHALLENGES AND CONSTRAINTS

**TB treatment initiation delays and interruptions affected up to 9% of pediatric TB cases,** largely because of supply chain challenges, poor access to pediatric TB formulations, public worker strikes, and health facility closures. SMILE staff consistently advocated with the NTP at national, state, and LGA levels, as well as with treatment facility staff for accelerated action on these issues.

**Inability to ensure the provision of HTS for all symptomatic or confirmed child TB cases affected up to 42% of children.** Barriers included shortages of HIV test kits, hidden charges related to HTS, health worker strikes, constraints in record keeping and data management, and the distance between HIV and TB services. To increase completion of high-priority referrals, closer engagement with HTS providers is needed to garner their support of

TABLE 1

TB SCREENING CASCADE FOR CHILDREN <18 YEARS	
Indicator	Total
Children screened for TB	11,125
Identified with TB symptoms and referred for TB diagnosis	2,553
Completed referral for TB diagnosis	1,767
Diagnosed with TB	466
Initiated on TB treatment	424
Completed TB treatment	316

TABLE 2

CHILD TB SCREENING AS AN ENTRY POINT TO HTS	
Indicator	Total
Children with TB symptoms tested for HIV and received results	1,475
HIV positive	29
Initiated on antiretroviral therapy (ART)	28
HIV positive (but TB negative)	9
Pediatric TB cases tested for HIV and received results	404
Co-infected (diagnosed with both TB and HIV)	20
Initiated on both TB treatment and ART	20

SMILE's efforts to usher all presumptive TB cases through prompt HIV testing.

## CONSIDERATIONS FOR FUTURE PROGRAMMING

The following insights are vital to future program development, especially in high-TB-burden countries with a concurrent HIV epidemic:

- The TB screening tool could be adapted to **specifically capture information about known exposure to household members or child caregivers with TB.** Since illness can be slow to emerge, caregivers should be questioned about TB or characteristic symptoms in the past two years. This will allow for prioritization of presumptive cases and reduce effort required for reverse screening.

- The TB screening tool could be adapted to **identify child contacts with active TB or HIV-positive children who are not receiving IPT**, to improve compliance with this important preventive measure.
- Although the national protocol supports the provision of IPT to TB-exposed children under 6, uptake is low and compliance is poor. This gap leaves vulnerable children without the proven protection they need and deserve. **Future OVC programming could support IPT coverage** through strengthening community-facility linkages and providing a range of proven adherence support interventions.
- **The integration of community-based HTS services, especially HIV screening, into TB screening activities** would narrow the gap on missed opportunities for single and dual diagnosis of active illness in children. Considering the urgency of finding HIV infection in children with TB symptoms, it is also important to advocate for a) increased co-location of TB and HIV services to increase uptake of HTS, and b) increased rapid HIV test kit inventory to address spikes in demand during accelerated CTBC activities.

## CONCLUSION

The SMILE CTBC initiative showed that programs designed to serve OVC households, through their community presence, network of CVs, and robust relationships with community influencers and child caregivers, can be very effective in detecting pediatric TB cases. Integrating a pediatric TB initiative into an OVC program leverages the skills, infrastructure, relationships, and credibility of a child-focused, community-based mechanism.

Through community education and household-level coaching, SMILE staff and CVs successfully tackled lack of knowledge and removed many physical, financial, and logistical barriers to diagnosis and treatment. Targeting high-TB-burden communities for CTBC produced higher yields, in comparison to broader targeting, which reached only OVC program beneficiaries.

**The results of this initial effort support the importance of providing ACF activities on a routinized basis to better serve identified hot-spot communities.** The use of a child-focused TB screening checklist allowed CVs to be systematic, objective, and accurate in their identification of presumptive TB cases. **The integration of community-based HTS services, especially HIV screening, into CTBC activities** would reduce missed opportunities for both single and dual diagnosis of active illness in children. Considering the urgency of ruling out potential HIV infection in children exhibiting TB symptoms, it is also important to advocate for a) increased co-location of TB and HIV services to increase uptake of HTS, b) increased rapid HIV test kit inventory to address spikes in demand during accelerated TB case-finding activities, and c) improved coordination and collaboration between the NTP and the national HIV program to ensure availability of relevant diagnostic tools and drugs.

Importantly, this effort strengthened SMILE's HIV mitigation mandate by purposefully tackling TB, which is the most likely cause of death among individuals with HIV, while using TB screening as an entry point for promoting HTS for children most at risk. A complementary funding stream allowed this PEPFAR-funded OVC program to provide life-saving pediatric TB services while identifying new pediatric HIV cases and getting them into care.

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