[Nothing for Us without Us (NUWU- Project )

[Stop TB Partnership, CFCS]

[September2014]

[Advocating for more involvement of TB infected/affected in TB care in Ghana.]
The West Africa AIDS Foundation continues to be a trail blazer when it comes to projecting the interest of key affected populations into the limelight and attention of policy makers and program framers. In an effort to ensure that the visibility and continuous interests of affected populations are paramount and factored into policy and programming, a one-day consultative meeting was held at the Ghana Institute of Engineers on the 18th of September, 2014. The purpose of the meeting was to provide WAAF a forum to inform and educate key personnel working in the field of TB care and control on a new TB program titled “Nothing for Us Without Us”, with the objective of promoting active participation of key affected populations in TB dialogue and programming. The event which marked the beginning of a full implementation of the TB program was funded by the global STOP TB partnership under the challenge facility for Civil Society window. The meeting brought together members of the affected population; government and private agencies; STOP TB partnership- Ghana, Country Coordinating Mechanism; Civil Society Organizations; and the Media. These diverse groups shared ideas on how key affected populations could be effectively supported to contribute to a meaningful dialogue in the country.

The event was spearheaded by a series of presenters and key note speakers who enlightened participants on the global and national picture of Tuberculosis care and management, including, the dynamics of the Global Fund’s new funding model, current challenges confronting TB-affected and infected-communities. The main facilitators of the program were Dr. Naa Ashley Vanderpuye-Donton, CEO of WAAF, Austin Arinze Obiefun, Developing Country NGO Representative to the Global Fund, Alex Boakye, Project Officer of WAAF, Dorothy Abudey, Regional TB coordinator, Genevieve Dorbayi, WAAF Board Member and a member of the International Union of TB and Lung Disease and Professor Kwasi Addo, Board Chairman of STOP TB partnership-Ghana.

Mr. Alex Boakye, the Project Officer of West Africa AIDS Foundation, opened the session by stating that the gathering provided an opportunity to bring together TB activists and advocates to
deliberate on how key affected population could be better represented in all matters affecting their welfare. The meeting was also to allow participants to network and gain an understanding of the CCM’s operational systems. A brief background of West Africa AIDS Foundation was presented to give attendees insight into WAAF’s vision, and mission including its operational areas. Mr Boakye highlighted some of the significant contributions WAAF has made and continues to make in support of the national response towards the elimination of Tuberculosis from Ghanaian communities. He added that, apart from the prevention, advocacy and empowerment programs the organization implements, WAAF with its onsite clinic also provides comprehensive treatment packages to community members.

**Global Fund’s new funding model**

The above topic was presented by Mr Austin Arinze Obiefuna, Developing Country NGO Representative for the STOP TB Partnership. He described the Global Fund as an independent public-private partnership institution constituted by governments, multi and bilateral agencies, civil society organizations and members of the affected population. The Fund existed to mobilize resources for the implementation of programs aimed at ensuring universal access to care and treatment to achieve improved health and economic standards. According to Mr. Obiefuna, the Global Fund served as a financial institution to mobilize funds to undertake developmental health programs. Consequently, it could not be regarded as an implementing agency. The Fund supports countries through their various agencies to curtail the spread of malaria, Tuberculosis and HIV/AIDS and also mitigate its impact on communities. Mr Obiefuna further described the structure of the Global Fund and highlighted some of the guiding principles regulating its functions. These principles included supporting programs that reflected national ownership, evaluating proposals through independent review processes and pursuing an integrated and balanced approach to prevention and treatment.

On the subject of the Global Fund’s new funding model, Mr Obiefuna indicated that it required a submission of a single concept note on TB and HIV. The submission must reflect inputs from the affected population. The new funding model was based on a framework of three main pillars, namely, patient-focused, bold policies and operational research. It is rooted in the notion of ensuring bigger impact, developing ambitious vision and ensuring flexible timing. Mr Obiefuna also discussed the CCM’s operation and identified its role under the new funding model. Participants were allowed an opportunity to contribute to the discussions and ask probing questions to gain further clarifications on how the CCM’s intended to integrate affected population into its operations.

**Why there is a need to actively involve key affected population**

A member of the International Union of TB and Lung Disease, Madam Genevieve Dorbayi gave a key note speech on how essential it was to fully involve the affected communities in decisions on TB care. She said the views and interests of key affected populations cannot be properly
represented without their active involvement in program planning and implementation. Madam Dorbayi added that healthcare personnel could not really understand the situations and conditions of key affected people without the latter group being at the table to enrich the discussions with their own personal experiences. She said the world has now come to acknowledge the need for health program implementers to be more conscious on the principle of inclusiveness when planning and implementing health programs. This, she said will allow for maximum impact on beneficiaries.

The NUWU project

The chief executive officer for West Africa AIDS Foundation, Dr NaaAshiley Vanderpuye-Denton took her turn to inform participants about the NUWU project, by describing its content, purpose and overall outcome. In her opening remarks, she indicated that the fight to control TB spread will be incomplete without actively involving and engaging key affected populations and patients. Without the participation of community representatives, including beneficiaries, health programs cannot achieve it ultimate goal of improving health standard in these communities. Dr Naa described the project as one that seeks to empower the affected communities by building their capacities to better represent themselves and contribute meaningfully to policies and programs regarding TB control. The project also aimed at helping the less powerful and vulnerable to have a voice in the country’s political and social discourse. She said, often times, these marginalized groups were not fully engaged in dialogues because of the perception that they lacked technical expertise and appropriate related knowledge to make significant contributions at meetings involving high powered technocrats.

Dr. Vanderpuye-Donton argued that the lack of technical expertise should not be used to justify the continuous neglect of affected populations in program development and policy formulation. According to her, the NUWU project will bridge this gap by equipping affected populations with the appropriate tools to meaningfully influence policies. The program will offer a series of workshops to train members of the target groups to enhance their knowledge on TB, update them on the latest developments in TB management, and build their communication skills to heighten their confidence levels. These workshops will be more practical in their approach by giving participants lots of opportunities to develop problem and assessment skills.

The ultimate goal of this 12-month project was to have a TB representative as a member on the CCM. In her concluding remarks, Dr. Vanderpuye-Donton suggested that the only way to achieve this goal was via effective collaboration and cooperation with key stakeholders. She therefore urged participants to support and help WAAF to achieve the project goal.

TB control in Ghana; Greater Accra Regional update

The final presentation was by the Greater Accra regional TB coordinator, Madam Dorothy Abudey. She gave a brief overview of TB control in Greater Accra including current efforts to manage and forestall its spread. She said Greater Accra has doubled its efforts in the fight against
TB, especially through collaboration with private health facilities and civil society organizations. According to her, drugs for TB treatment were available at every District and Regional hospitals in Greater Accra. She added that although Greater Accra had the highest TB incidence in the region, it has made significant strides by reducing the rate of infection.

**Messages from key invitees**

Professor Kwasi Addo, the Board Chairman of STOP TB partnership-Ghana further gave participants insights into CCM’s operations and functions of the STOP TB partnership-Ghana. According to him, the World Health Organization has over the years pegged Ghana rate of TB incidence at 92 cases per 100,000 population; however a recent prevalence survey conducted by the Ghana Health Service, revealed the actual rate to be 286 cases per 100,000 populations. Thus with a population of about 25 million, there are about 72,000 TB cases in the country. Professor Kwasi Addo indicated that these new findings must be an issue of concern to everyone.

Finally, a member from TB Voice Network took the podium to highlight some of the main challenges facing the TB communities and welcomed the NUWU project as coming at the right time to address some of those challenges.

The program came to an end with participants feeling enthused expressing their optimism, desire and willingness to support and lead the crusade in the fight to control TB spread.
WAAF Launches New TB Project
The West Africa AIDS Foundation [WAAF], has launched a new tuberculosis [TB] project dubbed Nothing For Us Without Us[NUWU] with a call on Civil Society Organizations [CSOs] in the fight against communicable diseases to maximize efforts and resources to effectively eradicate the disease.

Launching the Project in Accra, Dr. Naa Ashiley Vanderpuye-Donton, the WAAF Medical Director, said the goal of the NUWU Project is to advocate for more involvement of TB affected persons to occupy positions in the newly created platform for fighting the disease.

Dr. Vanderpuye-Donton noted that although much has been done in the fight against the disease in the past, there is still more to be done by the government, donors, CSOs, opinion leaders amongst others.

She pointed out that the failure to involve TB affected patients to serve on TB platforms has been a constraint in the fight against the disease.

According to her, the patients can contribute their quota effectively in championing the courses of their compatriots if involved in the process.

The Holland trained Medical Officer mentioned that it is very important for them as a CSO to use the little amount of money given them wisely in these periods of dwindling funding from donor agencies and partners.

To this end, Dr. Ashley Vanderpuye-Donton disclosed that her outfit haven being working in the field for long, would employ the right representatives as well as use the US$ 17. 000 bid they won from the Stop TB Partnership, a Geneva based firm wisely to benefit the people for which the amount was donated.
She mentioned that apart from key affected persons, WAAF would also bring on board experienced Civil Society Groups and consultants to help in that direction.

She however bemoaned the current status of Tuberculosis prevalence in the country and called for a more collaborative effort in the fight to end the canker.

She urged the TB affected persons to ensure their voices are heard rather than sitting idle when nominated to sit on the platform. They must fight hard as they are representatives of their compatriots.

The WAAF Medical Director called for them to be well equipped in order to understand well the standards within the mechanisms as the work she noted has been made easy through the lobbying of donor agencies and policy makers.

She promised that the process of choosing representatives to serve on the newly created Country Coordinating Mechanisms [CCM] would be transparent and that she is hopeful they would work assiduously to ensure the success of the one year project.

The launching held at the offices of the Ghana Institution of Engineers brought together personnel from the medical field, academia, CSOs in health and the media.

The CCM is a 25-member platform composed of the academia, government, CSOs, donor agencies as well as key affected TB persons.

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