

## THE BIENNIAL REPORT, JUNE – DECEMBER, 2018



**Compiled by;**

Miir Michael

**Technical ADVISOR, HIV/AIDS, Disability and Gender based Violence (GBV)**

Masaka Association of Persons with disabilities Living with HIV/AIDS (**MADIPHA**)

P.O. Box 1232 Masaka - Uganda, Muto Complex, Room 16 Main floor, Kampala Road,

Masaka Town. **Email:** [miir\\_m@yahoo.co.uk](mailto:miir_m@yahoo.co.uk), **Web:** [www.madipha.webs.com](http://www.madipha.webs.com),

**Mob:** +256702490912 (*whatsapp*)

## **1.0 Introduction**

The biannual report is from 1<sup>st</sup> June to 31<sup>st</sup> December, 2018. It highlights the report's background, MADIPHA's outstanding achievements, challenge (s), future plans for 2019 and conclusion remarks.

## **2.0 Background**

The Human Rights Advocacy Program (HRAP) is under the Institute for the Study of Human Rights at Columbia University in the City of New York, it brings together outstanding practicing human rights advocates from all walks of life to share their experiences as well as attend lectures of their choice, learning various skills in presentations, proposal writing, hold workshops for several participants on and off campus, interact with the US based advocates and organizations that supports human rights activities.

Thus, between August to December, 2017, I got an opportunity to represent MADIPHA and attended this amazing program.

The course did not leave me the same and our organization. Therefore, this biannual report shows how I have implemented the ideas learnt from the course and how our networking with our partners I met in USA is enhancing our advocacy work in Uganda.

## **3.0 Key achievements**

### **a) Successful projects**

As MADIPHA we cannot do it alone. That's why we are so grateful to people who have joined us in breaking down barriers and challenging attitudes, so that people with disabilities living with HIV/AIDS and TB can enjoy their full human rights.

### **i) Tweyambe project**

One of the sessions, I attended was on proposal writing. I used the same skills to write a project entitled Tweyambe (Lets help each other).

Consequently MADIPHA was awarded a grant. Hereafter MADIPHA in partnership with ViiV Health Care is implementing a 2 Years project 2018/2020 titled "TWEYAMBE" ( lets help ourselves) aims at streamlining the response to sexual violence (SV) and sexual reproductive health rights (SRHR) in Masaka District by strengthening local capacities and scaling up protection and justice with emphasis on Girls/Women With Disabilities (GWWDs) and local leaders' participation.

In October, 2018 the project finally kicked off with a baseline study called *"THE DIAGNOSTIC AND BASELINE STUDY OF RESPONDING TO SEXUAL VIOLENCE (SV) AND SEXUAL REPRODUCTIVE HEALTH RIGHTS (SRHR) AMONG GIRLS AND WOMEN WITH DISABILITIES (GWWDs) IN KIMANYA/ KYABAKUZA, KABONERA AND MUKUNGWE SUB COUNTIES – MASAKA DISTRICT"*

The baseline survey report is available in case you need a copy.

## **ii) Leave No One Behind in TB Project**

MADIPHA has received a Small Grant Funding from Treatment Action Group (TAG) to implement a twelve (12) month advocacy campaign project in five (5) districts namely Masaka, Lwengo, Buomansimbi, Kalungu and Ssembabule.

It is entitled; "Leave No One Behind in TB. Involve the disability community" We are interested in beginning the conversation at national and international level to see the mainstreaming of disability in TB prevention, testing, treatment and care.

## **iii) Inclusive elections advocacy strategy for Uganda, 2018 – 2023**

We have worked so tirelessly with Ms. Lillian Namukasa-Program Officer; Research, Information and Documentation, National Council for Disability (NCD) to finalize the first ever Inclusive elections advocacy Strategy for Uganda.

The strategy aims to create an enabling environment for the persons with disabilities in Electoral processes in Uganda by 2023. The strategy was launched on 19<sup>th</sup> December, 2018.

### **b) Workshops/ Trainings**

The experience acquired in human rights and advocacy, I am still sharing it out with other Disabled Peoples' Organizations (DPOs) and Civil Society Organizations (CSO) through trainings and workshop. Below are some of the trainings I have facilitated;

The World Vision Uganda, Buikwe ADP organized the Life skills training for primary pupils. This training which I facilitated targeted a total of 48 pupils; 24 boys and 24 girls from grades 3 – 6 and some school teachers from 3Rs R/C, Kasokoso, Kungu Bahai, Biboo C.O.U, and Nansinya C.O.U Primary, Kawolo Division, Lugazi Municipality, Buikwe District. The training which was held at Nansinya C.O.U primary from 8<sup>th</sup> – 9<sup>th</sup> November, 2018, aimed to empower both boys and girls in primary schools with social survival skills.



*Some of the pupils who attended the life skills training and their teacher (standing)*

From 22 – 23 November 2018, Centre for Sign Language Bible Translation Network Uganda (CEBTRAN) a Deaf –led Christian Organization whose main objective is to deliver the words of God to Deaf people in a simple format that they can understand through translation of text scripture into Uganda Sign Language Scripture, invited me to facilitate a training held at Eureka Hotel whose objective was to build the capacity of the Board and the staff to be as effective as possible to get the best results in human rights, advocacy, conflict mitigation, exhibiting best leadership styles, project planning & implementation, governance, and resource mobilization and fundraising, Monitoring, Evaluation and Learning.

Sense International Uganda, with support from Big Lottery Fund (BLF), organized a three (3) day training from 5<sup>th</sup> to 7<sup>th</sup> December, 2018 at Jobia Hotel for 20 staff and board members of Uganda Parents of Children with Deaf Blindness (UPDBCA) and National Association of Deafblind people in Uganda (NADBU) on Advocacy. The training which I facilitated aimed at; a) developing a training need assessment to identify advocacy training areas b) developing advocacy training content for training staff of partner Organization UPDBCA and NADBU, c) training staff of Uganda Parents of Children with Deaf Blindness (UPDBCA) and National Association of Deafblind people in Uganda (NADBU) on Advocacy and; d) supporting/guiding the development of the advocacy plan for partners.

### c) International Conference



I am grateful to Treatment Action Group (TAG) that supported me to represent MADIPHA in the 49<sup>th</sup> Union World Conference on Lung Health held from 24<sup>th</sup> – 27<sup>th</sup> October 2018 in the Hague, Netherland. The theme of the conference "Declaring our Rights: Social and Political Solutions. During the conference, I made a presentation about MADIPHA's role in Disability, HIV/AIDS and TB.

I also ran an individual activism campaign that was calling upon all stakeholders in TB to start the conversation on TB and Disability. As TB causes disability and People with disabilities are affected and infected by TB, neither an inclusive program nor an integral rehabilitation aspect is designed for them.

### d) Fundraising

MADIPHA stands with all vibrant community of friends and supporters who stand with us in everything we do, whether volunteering, advocating, donating or participating in different events. Their support sustains our cause and inspires us all.

Therefore, on this note, on behalf of MADIPHA we wish to thank all members of St. Michael's Episcopal Church, 225 W. 99<sup>th</sup> St. New York, NY 10025 for supporting us in this fundraising campaign through selling our handmade crafts from our members to improve their household incomes.

## **4.0 Challenges**

High level of stigma associated with Disability, HIV and TB causes this unique population to suffer greatly from discrimination

Inadequate education surrounding the needs of those with disabilities greatly decreases their livelihoods hence making it hard to access HIV and TB treatment

The demand to our services has increased yet, we still have limited funding to reach all members.

## **5.0 Future plans for 2019**

In 2019, our focus will see us popularizing these 21 recommendations for partners and stakeholder to address Disability and TB in the world. We also call upon all funders to support us achieve our goal.

As you maybe aware, MADIPHA is the only organization that is run and managed by people with disabilities living with HIV/AIDS in Uganda. Since 2009, we have learnt a lot and what we recommend below comes from our long involvement in the HIV/AIDS work which we highly recommend that it will work very well in the STOP TB campaign.

MADIPHA believes that in order to address the challenges faced by persons with disabilities affected and infected by TB and its consequences, we recommend the following to be considered in all TB programming, implementation and funding.

### *1. Making equal access and participation in TB programmes a reality*

CRPD (3) clearly lays out the rights of people with disabilities to equality and non-discrimination (Article 5); equal access to education, including TB information (Articles 9 and 24); justice (Articles 12 and 13); health, including sexual and reproductive health, TB services and rehabilitation (Articles 25 and 26); and the right to freedom from exploitation, violence and abuse (Article 16). Therefore, inclusion and participation of people with disabilities are integral to these rights. Several

innovations have advanced inclusion in TB-related programmatic areas and hold potential for adaptations in other contexts.

*2. Disability-inclusive policies and programmes*

National strategic plans or frameworks on TB set out the response of countries to the epidemic. Legal frameworks provide for the rights of people with disabilities to some extent and yet fall short on providing guidance for implementation.

*3. Including people with disabilities in other key programmatic areas*

People with disabilities need to be included in other key programmatic areas.

*4. Disaggregating national TB surveys via sex, age and disability*

Data and research on disability are crucial to inform disability-inclusive programming. The need to improve routine data collection and focused research on disability has been highlighted in several documents. National surveys, including those on TB, need to include disability indicators that can be disaggregated.

*5. Assessing accessibility of TB services through a disability audit*

The accessibility of services, especially those for sexual and reproductive health and rights, TB and HIV, is related to the social and structural barriers that people with disabilities may experience. Services need to implement the CRPD principles of universal design and reasonable accommodation. Simplified tools, such as a disability audit of services, can help to identify and then address issues of accessibility.

*6. Evaluating TB and health rights interventions for people with disabilities*

Evaluations of TB health rights services in the context of resource-poor settings is still very scarce. Evaluations of a pilot project in this context show promising results, however, and highlight innovative approaches for implementation and evaluation.

*7. Training and supporting educators of people with disabilities to address misconceptions and strengthen access to comprehensive TB education*

People with disabilities often lack access to comprehensive TB education due to negative attitudes and misconception, or due to a lack of skills and resources on how to provide comprehensive TB education in accessible formats.

*8. Adapting mainstream TB health rights approaches to include people with disabilities*

Including people with disabilities requires adaptation as well as rights awareness through developing simple guide on how to explain rights in simplified formats and tools to provide access to TB screening and testing for people with intellectual disabilities through a simplified picture book and guide.

*9. Empowering people with disabilities as agents of change by appointing them as leaders in inclusive TB programmes*

Initiatives that have successfully included people with disabilities in the response to TB highlight the importance of leadership and the empowerment of people with disabilities and their organizations.

*10. Enabling peer education and support for people with disabilities*

Some groups of people with disabilities are hard to reach. Peer-led or peer-supported programmes have been shown to overcome communication barriers such as those experienced by people with hearing impairment.

*11. Training people with disabilities to strengthen legitimate knowledge and rights awareness*

People with disabilities can be advocates for their own rights.

*12. Developing accessible information material in areas of rights protection for adults and children with disabilities, TB information and TB prevention and treatment*

Information on TB and health rights has to be universally designed or, where this is not possible, reasonably accommodate access. The Gay and Lesbian Archives provide an interesting example of how to adapt information material to make it accessible for young people with hearing impairment

*13. Integrating health rights and TB services into disability-focused programmes and the work of disabled people's organizations*

Disability-focused initiatives and organizations need to include health rights and TB elements within their programmes.

*14. Developing integrated and comprehensive TB services*

The World Health Organization (WHO) guidelines build on the WHO Global Strategy on People-Centred and Integrated Health Services, which present a fundamental shift in the way health services should be funded, managed and delivered. The concept of integrated health services includes the idea that health services "are managed and delivered in a way that ensures that people receive a continuum of health promotion, disease prevention, diagnosis, treatment, disease management, rehabilitation and palliative care services ... according to their needs and throughout their whole life". Current TB policy and programmes provide little guidance, however, on how to integrate the rehabilitation aspect. Several innovative approaches can inform the needed shift.

*15. Approaches to integrating disability screening into routine chronic care*

The identification of functional limitations and disability is the first step in linking people to care. In many countries, however, health-care workers are not trained in and cannot use simple screening tools to identify people with potential disabilities. The Centre for Global Mental Health and the Canadian Working Group on AIDS and Rehabilitation provide examples and tools to identify functional limitations and disabilities in the context of HIV.

*16. New models of integrated TB and rehabilitation care*

Integrating rehabilitation into chronic care requires a shift in chronic care models towards more integration. Current models may integrate some aspects of rehabilitation, such as mental health, but this must be widened to include other aspects. Chetty's model of integrating HIV and rehabilitation care can provide guidance on how to analyse existing care, identify opportunities for integration on

all levels and highlight the variety of disabling effects that people living with TB may experience.

*17. Training of rehabilitation professionals or health-care workers to provide mitigating or rehabilitative services in the context of TB*

Integrating rehabilitation services and chronic TB care requires a better understanding of the intersection of disability and HIV and the feasible approaches to delivering rehabilitation interventions.

*18. Providing information to and supporting people living with disability who have TB or acquire disability due to TB HIV to actively engage in their own care management to prevent and mitigate impairment*

People living with disability who have TB or acquired disability due to TB need to develop health-promoting practices that can help to prevent or mitigate impairment over time. Pilot projects using health information and home-based exercises have shown promise in reducing the risk of co-morbidities, such as ischaemic heart disease and mobility limitations.

*19. Integration and use of e-health tools advancing early identification of disability, linkage to care and learning tools*

Advancing the integration of rehabilitation into TB care through improving skills and knowledge can be accelerated through the use of Internet-based education. In recent years, app-based screening tools for resource-poor settings have been developed for vision, hearing and mobility. These can be used by lay health-care workers and include automated linkage to local rehabilitative care and support.

*20. Delivery of affordable and appropriate assistive devices*

The integration of rehabilitation into TB care may include the need to provide assistive devices. These must be adapted to individual needs and can be costly. Decades of experience in providing affordable assistive devices in resource-poor settings can be accessed through existing national and international nongovernmental organizations that work with people with disabilities.

### *21. Using alternative service delivery modes*

Within the past decade, service delivery models that use a task-shifting approach to deliver rehabilitation services in resource-poor settings have been evaluated in the context of HIV. These approaches may be feasible alternatives in areas that lack skills in rehabilitation. Existing approaches such as home-based or community-based rehabilitation to reach people with disabilities having/ or disabled by TB, which have been widely applied in resource-poor settings outside the field of TB, can be used to inform how rehabilitation can be delivered and integrated with TB care in a feasible manner.

## **6.0 Conclusions**

I wish to thank all board members and staff of MADIPHA for embracing some of the theories we are implementing and also the projects we are undertaking. I also wish to thank Stephanie Grepo, Director, Capacity Building, HRAP, for the continued support whenever we reach out to her.

To TAG thank you so much for making our *"LEAVE NO ONE BEHIND IN TB. INVOLVE THE DISABILITY COMMUNITY"* Campaign a reality and we believe it will yield more tangible results to all people with disabilities in the world,

You too, can make a difference and change the lives of people with disabilities living with HIV/AIDs in Uganda.

Allow me on behalf of MADIPHA to wish you a HAPPY and FRUITFUL 2019.