Spring 2023 Professional Fellow

Nina H Mago Name:

Country: Uganda

Job Title and Employer: Founder and Chief Executive Officer,

Purple Bench Initiative (PBI) Uganda

Project Title: Enhancing Participation of Young People Living with Epilepsy in

Education in Uganda

Problem: The national prevalence rate of epilepsy in Uganda is alarming, 2.5 times the worldwide average, indicating that over 770,000 Ugandans are living with the condition (Ndyabahika & Mugaga Tukacungurwa, 2023). However, in Uganda, young people with epilepsy are not participating equally in education, due to the deep-rooted stigma and discrimination they experience in school and the community. High self-esteem is often linked to improved learning and career outcomes. The fundamentals of self-esteem are cultivated throughout childhood, in and out of the school setting. School staff typically lack the knowledge and correct information about epilepsy and contribute to the problem by sending away a child who experiences a seizure in school. Bullying and exclusion from class activities significantly affects young people with epilepsy's self-esteem. Due to poverty in the community, parents prioritize other children over the child with epilepsy, which has a further negative impact on the child's self-worth and strengthens the misconception that a child with epilepsy is not 'smart enough' to attend school.

Project Objective: Nina aims to increase the self-esteem and inclusion of young people living with epilepsy in Uganda by promoting awareness using a combination of interactive school assemblies and community meetings.

Project Description: Nina's project will create epilepsy awareness to affect attitude and mindset change and to build esteem and confidence of young people with epilepsy so that they can actively participate in issues concerning their lives. To do this, Nina will organize interactive school assemblies for students facilitated by individuals with epilepsy who share their personal experiences. The event will end with a final quiz competition and the three best young participants will be awarded branded token gifts.

The project will be centered in Masaka District and target four primary schools, three secondary schools, and three training institutes. To complement the assemblies, Nina will hold discussion sessions with the teaching and non-teaching staff and awareness meetings with caretakers. Additionally, Nina will share awareness information on local radio and through social media.

Awareness materials will be based on Social Behavior Change Communication strategy, which is used to promote knowledge and change attitudes and beliefs. Materials will focus on demystifying epilepsy, first aid, and "dos and don'ts" with the input from young volunteers living with epilepsy and Purple Bench Initiative Staff. Nina will use pre- and post-evaluations to assess the impact of the session with each group of students, teaching and non-teaching staff, and caretakers.

Reference:

Ndyabahika, D. and Mugaga Tukacungurwa, J. (2023). Study Reveals Epilepsy Prevalence and Treatment Barriers in Uganda, Urgent Need for Awareness and Resources.











