



A FIRST STEP IN *Uganda:*

Understanding Services for People with Down Syndrome

Michael Okiro-Emadit and 3-year-old Nabiro, already a star in her community with a smile that can brighten anyone's day

“MPOLA MPOLA” IS A UGANDAN COLLOQUIALISM THAT LITERALLY MEANS “SLOWLY SLOWLY” AND IMPLIES THAT THE GOAL OR DESTINATION WILL EVENTUALLY BE ACHIEVED. THIS IS HOW THE GLOBAL LIVINGSTON INSTITUTE (GLI) SUMS UP THE GROWING INITIATIVE AND MOVEMENT THEY ARE CREATING WITH THE GLOBAL DOWN SYNDROME FOUNDATION FOR PEOPLE WITH DOWN SYNDROME IN UGANDA.

“WHAT MAKES THIS such a formidable partnership is that you have a research institute like the GLI, which understands Uganda and has built really strong relationships within the community, working with an organization like Global that really understands the global Down syndrome issue,” said Jamie Van Leeuwen, GLI’s founder and CEO. “Together we learn about the gaps and services that already exist for persons with Down syndrome and who the best leaders to address these issues are in the Ugandan community.”

The GLI’s mantra is “Listen, Think, then Act.” Global’s mantra is “never for us without us.” Combined, these have led to a coalition of diverse organizations evaluating services for people with Down syndrome including:

- The Special Presidential Assistant Directorate of under-privileged/disabled for the Republic of Uganda
- Embrace Kulture, a nonprofit working to improve education for children in Africa with developmental disabilities
- The Ugandan Ministry of Education-Special Needs Education
- ChildFund® International, an organization that works to ensure children reach their full potential
- The Uganda Down’s Syndrome Association (TUDSA)
- The Honorable Consul General of the Republic of Liberia

“TUDSA is pleased to have attracted the support of GLI and Global in Uganda,” said Michael Okiro-Emadit, TUDSA Country Director. “We would like Uganda to become a center of excellence for bringing services to people living with Down syndrome. This is doable if we all put our hands and minds to it.”

Using more than 300 hours of discussions specific to the needs of people with Down syndrome, GLI created a report with a series of recommendations to improve the lives of people with Down syndrome, including suggestions for improving health care and education and raising awareness. The report also acknowledges existing gaps, such as scarcity of resources, difficulties identifying and diagnosing Down syndrome, and how to provide specialized medical care.

“We hope to publish GLI’s groundbreaking report as a white paper,” said Michelle Sie Whitten, President and CEO of Global. “In the meantime, it sets the stage for a three-year initiative that has the capacity to significantly improve, and ultimately shift, the way services are delivered to people with Down syndrome and to grow Uganda as a model country in taking a leadership role in this area.”

Mobilization has already started to take place. On March 21, 2017, GLI and Global helped Uganda join the world in celebrating its first World Down Syndrome Day with events in Entebbe, Kampala, and Kabale. In 2018, the coalition hopes to celebrate a myriad of projects, including the translation of important Down syndrome resources into key Ugandan languages.

“I’m not sure how ‘mpola mpola’ will go,” laughed Whitten, “but we will certainly take things step by step, working with GLI and the wonderful organizations and people in Uganda.” ●

As Country Director for The Uganda Down’s Syndrome Association, Michael Okiro-Emadit is a champion for individuals and families of those with Down syndrome. Here, he is shown with primary school students (from top) Doreen; Kate Sullivan with the Global Livingston Institute, Naiga, and Naiga’s mother; Nabatazi; and Oboo, Doreen, and Joyce.

