

I am privileged to stand before you a vision-driven advocate of disability, functional Education Secretary of South Sudan Association of the Visually Impaired and as the situational ambassador of my country. Advocacy is my passion, and equality is my vision.

If you don't mind, ladies and gentlemen, please allow me to guide you through the current state of disability and people with disabilities in the world's newest country, South Sudan, and the work my organization, South Sudan Association of the Visually Impaired, is doing.

South Sudan Association of the Visually Impaired [SSAVI] is a non-governmental, not-for-profit national organization that was founded by visually-impaired people in 2010. At the time, southern Sudan was on the verge of acquiring its independence from Sudan. Meanwhile, SSAVI sought equal rights for people with disabilities and particularly for people with visual impairments through programs generated and directed toward those objectives. This idea was born in response to the poor conditions the blind live in and community aspirations of gaining respect for their dignity, equal rights and opportunities.

Our membership is open to all visually impaired people in South Sudan. Currently, we have about one thousand members in three states, plus the capital, Juba, and we are planning to extend to the other parts of the country.

Our organization has memberships with South Sudan Union of People with Disabilities [SSUPD], the South Sudan NGO Forum, as well as African Union for the Blind and is in the process of acquiring membership to the World Blind Union.

Our Role:

Our work focuses on raising awareness of visual impairment, policy, advocacy and empowerment of the blind; and it emphasizes the need for their inclusion in government plans. We also focus on the private sector, as their programs affect the blind in one way or another.

- We conduct triangle programs that target the blind and their families, society and policy makers.
- We conduct awareness-raising campaigns to help sensitize society when it comes to disability. We do this by organizing social events, workshops and more importantly, by using media (i.e. local televisions, radios and newspapers).
- Equally important, our members play a critical role in awareness-raising campaigns by reflecting a positive image of the blind, contrary to the common perception of vulnerability.

Advocacy:

We also advocate and lobby for recognition, protection and promotion of the rights of people with disabilities by focusing on policy makers through face-to-face meetings,

workshops, media etc. We advocate on behalf of individuals, organizational initiatives and work with organizations with similar interests, or with one or all of the organizations under the South Sudan Union of People with Disabilities umbrella.

In 2015, we held six workshops and community dialogues in South Sudan's capital, Juba, and the main stakeholders were legislators, secondary and primary school teachers, local administrators and religious leaders. Furthermore, we advocate for recognition, protection and promotion of the rights of people with disabilities. By providing reasonable accommodations and accessibility at the forefront of our advocacy, and by maintaining a gender-sensitive environment, we consider nondiscrimination as a core principle. We are working to empower individuals who are blind by boosting their self-esteem and enhancing their capacities.

Lack of awareness and inaccessibility, in addition to lack of legislation and policy are major obstacles that obstruct people with disabilities from participation in society. Thus, people with disabilities become dependent on their families if they can cater to their needs, and if not, they are neglected; neither of these are positive outcomes. Therefore, we advocate and work to empower the blind.

Organizational Development:

Our organization develops and implements programs that aim at socio-economic and political empowerment of the blind. These programs emphasize the importance of participation in the decision-making processes directly or by selection of representatives of their choice without interfering with their freedom to exercise such right.

We develop and implement such programs by facilitating an environment conducive to participation and empowerment. For example, we conduct mobility training and provide microloans to those who have small businesses. Further, we involve the families in the process by building long-term, consultative relationships.

- We create programs that aim toward social inclusion and economic empowerment of the blind.
- We create an environment that encourages peer-to-peer counseling among the blind. We also provide counseling to people with disabilities and their families, especially those who acquired their disability at a late stage in life.
- We conduct workshops, campaigns and dialogues, as well as organize events that help raise disability awareness. We also facilitate fun activities for people with disabilities and the community.
- We speak out against violations of the rights of people with disabilities and inform people with disabilities on their rights.
- We identify problems and find solutions. For example, some negative misconceptions such as curses, bewitchment and viewing disability as a medical condition etc. are the main reasons for discrimination against people with disabilities.

Hidden Ability Melody:

Besides using office structure to make our vision a reality, we also incorporate talent in our programs. Thus, we founded Hidden Ability Melody--a music and drama group that was founded by young people with visual impairments under the association with the aim of finding talents among the blind and utilization of such talents in economic empowerment, awareness raising and a source of income for the association.

Conclusion:

Our vision is to realize a society where disability is no longer a source of discrimination but rather a source of appreciation of our human creation.

The understanding and treatment of the blind in our society:

While negative perceptions exist in our society, we observe that people are easy to appreciate, still strong with disabilities and are often associated with miraculous work. This foundation gives us the strength to work and the determination to continue this holy pursuit.

In terms of policy and legislation, we have worked with other disabled people's organizations and with the ministry of gender and social welfare, which deals with issues of disability in order to develop two main policies, which are the Disability Inclusion and Promotion Policy and the Inclusive Education Policy. These policies remain unenforced because they are yet to be passed by the legislature, nor thereafter signed by the president, as the law requires in our country.

Brief Overview about the History of the Country:

South Sudan is a rich country with an excess of untapped human and natural resources. This is mainly because there has been more than five decades of conflict inside and outside of the Sudan. In the Sudan, conflicts ranged from 1955 to 1972 and from 1983 to 2005, which then concluded with the Comprehensive Peace Agreement. The agreement granted the people of southern Sudan the right to vote in a referendum either to remain part of Sudan or become an independent country. About 99% of the population voted in favor of independence.

The last era left South Sudan with many potential pockets of conflict, which erupted as a result of failure of leaders to lead the nation in the right direction. In 2013, internal conflict exploded in South Sudan and ended in 2015; the latest occurred in 2016 but has now stopped. Throughout our history, the cause of all of this has been rooted in poor governance and politics. Undoubtedly, this history of conflict has resulted in high rates of illiteracy, widespread poverty and increased disability among the general population. And worse, the large number of people with disabilities lives surrounded by ignorance; they experience neglect and are extremely vulnerable in a country that lacks basic infrastructure.

A lot of national and international efforts have been exerted toward addressing the situation. Nonetheless, most of the programs do not address disabilities, although the situation affects people with disabilities most. For example, recent conflicts caused a lot of displacement among the population. And mostly people with disabilities became victims because they could not escape. In general, people already rarely escape in conflict. Ultimately, people with disabilities do not want conflict but want a fair chance when conflict occurs.

As they are abundant, people with disabilities become victims of unwanted conflicts and disasters. We understand that ignorance often leaves programs for the blind ignored and overlooked, and therefore, we had to step in to facilitate the process of inclusion and become a voice for the blind who are in need. We believe that a qualified disabled person who enjoys all of their rights without hindrance is the foundation of a stable, strong and progressive society.

We equally believe that development is an inclusive process that cannot take place without empowering all involved social actors. Empowerment of the blind is not costly but rather, creates employment in the process and future income by creating people who can pay taxes through private ventures or by joining the workforce.

Since our organization is in an environment where government support is lacking indefinitely, we are facing some challenges. These problems are manifested in areas like volunteer staff due to lack of constant source of income to keep our programs running, and thereby, this results in insufficiency of qualified personnel and equipment. Despite all of this, we have achieved records of success.

On behalf of my organization, I would like to invite any organization that is willing to work with us in the areas that we work in. We preach that people with disabilities are successful by nature and only need the environment and the right to demonstrate their- more often than not- hidden abilities.

According to the controversial 2008 census in the Sudan, the population of people with disabilities was reported to be 5.1%, which is highly disputed by the people of South Sudan for inaccuracy and also, disputed by people with disabilities. Also, the disability status analysis that was conducted by the National Ministry of Gender and Social Welfare also put the population of people with disabilities at 11% of the total population.

We recognize the existence of intersecting issues that we need to work on as a country and issues that people need to work on with us as the blind. Simply put, we all need each other to attain our goals.

A Little Bit about Me:

I am a disability rights advocate, and my work is to advocate for the rights of people with disabilities; and I am currently working to promote access to education for people with disabilities in general under the umbrella of SSAVI and SSUPD. I grew up in an

environment where disability is believed to be a curse--where dignity for people with disabilities is associated with isolation. Mainly, people believe seeing a disabled person on the street is a sign of economic incapacity of the family to which he or she belongs.

Disabled people are often believed to be beggars, and growing in this environment, especially when the family is not strong enough, they become beggars. Therefore, I might have been where people think I should be in my community. However, I was raised by a superwoman. When I was seen as a curse and a burden, she saw me as blessing and a gift from God; when I was seen as helpless and useless, she believed in my potential and treated me as a resource. When I was seen as disabled, she saw me as her child. She is my role model in advocating for the rights of people with disabilities. Because I know very well if someone hasn't defended my right, I wouldn't have been here today. And therefore, I believe that it is my duty to defend the rights of those who strive to find their place in the society--where they are denied such a right on institutional structure or of societal belief.

In my work as Secretary of Education, I have seen that people with disabilities have no support when they graduate from special school at all. Despite the free education, they can be rejected or neglected without any consequences. I know I can't fight this fight alone, and therefore, I joined SSAVI and SSUPD; and I am ready to work with anyone else who is willing to join me in this fight.

--Mauot Anyang, 2016