Down Syndrome in Africa

Lessons Learned From the November 2024 *Down Syndrome and Other Intellectual Disabilities Awareness Event,* Addis Ababa, Ethiopia

by Hewan Mulugeta Asfeha, Roel van der Veen[*]

Abstract

Down syndrome is a genetic disorder that affects around one in 1000 births worldwide. There is an overwhelming level of misconception in Africa regarding Down syndrome, which is often attributed to supernatural causes and as a punishment from God. Families hide their children with Down syndrome to avoid the scorn and discrimination from their community which consequently results in these children unable to access their basic needs of life including education. This paper will summarize the proceedings of the November, 2024 *Down Syndrome and Other Intellectual Disabilities Awareness Event*, the lessons learned, the gaps identified and also highlight proposed ways to move forward. The Down Syndrome and Other Intellectual Disabilities Awareness Initiative was established by Deborah foundation, a local non-profit based in Ethiopia in collaboration with the African Union and other international partners. In November 2024 a high profile event was held, centered on the message of self-advocacy and abilities beyond disability which also resonated with the 2023 World Down Syndrome Day slogan, "With Us Not For Us". The relevant changes achieved through the event are the changes in the knowledge and perception of event participants, the strengthening of networks between organizations working on Down syndrome all over Africa, empowerment of people with Down syndrome, clear identification of barriers to enhanced quality of life for people with Down syndrome and other intellectual disabilities. Through the lessons learned from the event, the initiative was able to develop a five-year strategy that will be able to alleviate barriers outlined above.

Keywords

Persons with Disability, Lessons Learned, Down Syndrome in Africa, Intellectual Disability.

1. Background

Globally, the prevalence of Down syndrome is estimated to be around one in 1000 births [1], these rates could be 2-3 times higher in low and middle income countries [2]. Down syndrome is a genetic disorder that occurs when there is an abnormal extra third copy of chromosome 21 and has three genetic variations, trisomi 21, the most common accounting for 95% of the cases, the second, translocation type and the third, mosaic type which causes less overt physical signs and symptoms [3]. Down syndrome can

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[*] Deborah Foundation Ethiopia. Corresponding author: hewan.asfeha@gmail.com.

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affect almost all organs of the body resulting in changes to one's physical features, cognition, immunity and organ development. Down syndrome is the most common genetic cause of intellectual disability [4] and is also associated with a long list of clinical conditions including congenital heart defects [5]. Social disadvantages including stigma and discrimination also contribute to the poor quality of life of people with Down syndrome in Africa [6].

In Africa, Down syndrome is often attributed to supernatural causes and divine punishment which pushes families to hide their children, denying them access to social interactions, education, and healthcare. Furthermore, the syndrome is also wrongfully attributed to the failings of the mother which results in divorces, single motherhood and loss of income to the household [6,7]. Hence, improving the quality of life of people with Down syndrome requires a comprehensive approach that includes raising awareness and combating the stigma in addition to facilitating access to quality healthcare and education [8].

2. The Origins of The Down Syndrome and Other Intellectual Disabilities Awareness Initiative

During the 2023 World Down Syndrome Day event, organized in Addis Ababa by Deborah Foundation, an Ethiopian NGO founded by a prominent family in 2019 after the birth of their daughter Deborah who has Down syndrome [9], valuable contacts were made with the Netherlands Embassy in Addis Ababa to the African Union (AU). The Embassy was impressed by the size and nature of the event (emphasizing abilities, instead of disabilities), and illustrating the foundation's capability to implement large scale projects not only in Ethiopia but also in Africa.

So the Foundation and the Embassy set out to create this initiative that aims to improve the lives of people with Down syndrome in Africa. The group grew to include other Embassies (Ireland, Italy, Germany), the European Parliament and the AU. AU Commissioner Minata Samate Cessouma of the department of Health, Humanitarian Affairs and Social Development, became much involved and the Godmother of the initiative. The various parties to the initiative put together their energy and finances to make the event possible.

The event took over ten months of planning and involved reaching out to relevant stakeholders, forming committees, discussing possible systems of implementation, planning out event content, and securing funding.

3. Event Proceedings

Day-1: Awareness Raising Conference, November 07, 2024.

The event attended by 350 participants, took place at Africa Hall, UNECA, the birthplace of The Organization of African Unity and was specifically chosen for its historic significance. The conference included speeches by Commissioner Sumate, Deborah foundation representatives and Ambassador Parfait Onanga-Anyanga, Special Representative of the Secretary-General to the African Union who all conveyed a message of unity and a call to action in creating an inclusive Africa for all individuals regardless of disability. Cultural dance performances were also presented followed by speeches and poems by people with Down syndrome, illustrating the importance of Self-advocacy, access to healthcare, education and social services.

Day-1: Down-and-Up Exhibition, November 07, 2024.

There were a total of 30 art pieces displayed by fifteen artists with Down syndrome and other intellectual disabilities. This segment allowed participants to network and reflect on the ability beyond disability of individuals with Down syndrome when they are given the opportunity.

Day-2: Practitioners Day, November 08, 2024.

The event, attended by 40 relevant stakeholders, was held at the Deborah Foundation compound and included a tour and the practitioners day forum. Presentations were made by self-advocates with Down syndrome from Kenya and Uganda, who shared their experience living with disability in Africa. A PhD student from the Netherlands, and the founder of Melu'e Foundation also offered valuable insights on the caregiver experience. The participants were then divided into focus groups to further breakdown the barriers faced by persons with Down syndrome and suggest solutions to better circumvent those barriers. The identified barriers from the focus group are as follows: lack of awareness and stigma, inadequate data, delayed diagnosis, lack of access to quality healthcare and special needs education services, lack of employment opportunities and lack of inclusive approach to policy making.

Suggested actions in the short-term include: awareness raising campaigns, engaging religious/traditional leaders, and organizing caregiver support groups. Additionally, long-term actions focused on inclusive policies, capacity building for healthcare, and education providers were proposed. Through this process the initiative was able to develop a five-year strategy.

4. Impact of the November 2024, *Down Syndrome and Other Intellectual Disabilities Awareness Event*

The impact of the event was monitored through utilizing two evaluation methods 1) focus group discussions, regarding the effectiveness of Day-1, which concluded the event a success in creating awareness and conveying the importance of inclusion and self-advocacy. 2) An online post-event questionnaire administered to 20% of Day-1 participants, as shown in Table 1.

Empowering People with Down Syndrome

The Day-1 conference was attended by 56 individuals with Down syndrome, of which over 30 were able to showcase their talents through dance performances, speeches, poems and art. The event provided a platform for these individuals to advocate for themselves, feel empowered, and be involved in the decision making process on topics that directly impact their lives.

Strengthening of Networks

The Initiative had established communication with 15 non-profit organizations supporting people with Down syndrome across Africa during the planning stage. Subsequently, the event was attended by representatives of five Ethiopian and two foreign Down syndrome NGOs, and representatives from the UN, AU and multiple embassies. The event concluded with pledges from the participants for future collaborations, exchange of best practices, and support for the initiative's five-year strategy.

Table 1. *Summary of demographics, knowledge, perspectives, and impact of the November 2024 Down Syndrome and Other Intellectual Disabilities Awareness, Day-1 event at Africa Hall, UNECA, Addis Ababa, Ethiopia.*

Category	**Metric**	**Response Breakdown**	**Percentage (%)**
Demographics	Caregivers of people with Down syndrome	32	45.71%
	Professionals in the field (Doctors, Psychologists)	7	10%
	Teachers	19	27.14%
	Deborah Foundation staff	4	5.71%
	Individuals with Down syndrome	4	5.71%
	Other (Government official, Private business owners)	4	5.71%
	Total	70	100%
Knowledge Assessment	Correctly identified Down syndrome as a genetic condition	55	78.6%
	Recognized all key challenges faced by individuals with disabilities	66	94.29%
Perspectives	Agree/Strongly agree: Equal access to education/employment	67	95.7%
	Agree/Strongly agree: Communities should be more inclusive	67	95.7%
	Agree/Strongly agree: Governments should implement stronger policies	68	97.14%
	Agree/Strongly agree: Healthcare professionals have sufficient training	29	41.4%
Event Impact	Felt more informed about inclusion rights	65	92.85%
	Felt that advocacy efforts can lead to positive change	68	97.14%
	Interested in future initiatives	70	100%

5. Conclusion and Future Steps

The Main Lessons Learned

Through the November, 2024 event of the initiative, it became clear that there is still a lot to be done to raise awareness and combat the stigma associated with Down syndrome in Africa, however, self advocacy and events such as these play a crucial role in addressing those issues. Additionally, the event also revealed the importance of collaboration between organisations working in this area across Africa as well as involving the private sector, government bodies and other international organizations to make sustainable changes that positively impact the lives of people with Down syndrome.

The achievements of 1 year of cooperation between Deborah Foundation, the African Union Commission, several European Embassies and the representation of the European Parliament in Addis Ababa have given this core-group the confidence to continue working towards its greater objective: to ultimately improve the lives of Africans with Down syndrome and other intellectual disabilities, as well as of their caretakers, around the continent. Based on the discussions on Day-2, a strategy was written for the years 2025-2030 that will assist in achieving the Sustainable Development Goals by 2030, all under the banner of "Leave no one behind" [10].

To achieve this overarching objective, the Strategy distinguishes 5 sub-objectives: 1) to raise awareness further, across Africa; 2) to help implement the AU Guideline on Disability Inclusion [11]; 3) to strengthen existing African organizations and networks working in this field, and help create new ones; 4) to increase knowledge and organize systems for exchange of best practices in Africa, and connect these to relevant systems outside Africa; and 5) to mobilize resources, and make improvements in the various relevant fields.

The initiative hopes to launch its Five-year Strategy officially, and to attract sponsorship, at the upcoming World Disabilities Summit in Berlin, Germany, April 2025. This should give the initiative the broader attention it needs to continue to improve the lives of Africans with Down syndrome and other intellectual disabilities, and their caretakers.

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