

# Remarks by SRSG Parfait Onanga-Anyanga The Down Syndrome and Other Intellectual Disabilities Awareness Event 7<sup>th</sup> Nov 2024 African Hall, UNECA -Addis Ababa Ethiopia (Check against delivery) \*\*\*\*\*\*\*\*\*

I don't know how do you fill but I am moved to the core. Moved by the deep sense of humanity that these children embody. They certainly remind us that we are all one, though different.

- Your Excellency Ato Abadula Gemeda, Founder of Deborah Foundation,
- Your Excellencies, the Permanent Representatives of the Netherlands and Ireland,
- Your Excellency, Ambassador Minata SAMATE CESSOUMA Commissioner for Health, Humanitarian Affairs and Social Development, with us both virtually and in spirit, as the Godmother of this amazing initiative,
- Distinguished Representative of Africa Celebrate and co-sponsor of today's event,
- Dear partners,
- Distinguished guests, ladies, and gentlemen, Dear friends,

I am delighted to join you on this auspicious occasion, which has achieved its main purpose: to raise awareness and advocate for the rights of children with Down syndrome and other intellectual disabilities. This is an ideal platform for knowledge exchange on best practices among organizations and professionals.

Allow me to begin by acknowledging and warmly congratulating Deborah Foundation, a nonprofit organization founded in 2019 by His Excellency Ato Abadula Gemeda and his family. The Foundation's commitment to improving the lives of children born with Down syndrome & other intellectual disabilities through comprehensive health care, inclusive education and policy advocacy is truly inspiring.

I commend you for this remarkable achievement, which is consistent with the core values of the United Nations and, If I may of the African Union, in furtherance of human dignity, and justice for all.

More specifically, the UN Disability Strategy initiated by the Secretary-General in 2018 "reaffirm(s) that the full and complete realization of the human rights of all persons with disabilities is an inalienable, integral and indivisible part of all human rights and fundamental freedoms".

### Ladies and Gentlemen,

The estimated incidence of Down syndrome is 1 in 1,100 live births worldwide. Each year, approximately 3,000 to 5,000 children are born with this chromosome disorder.

We are most grateful to Debora Foundation for its leadership role in raising awareness about Down syndrome and other intellectual disabilities. Your trailblazer work is aligned with the United Nations's call to 'Leave No One Behind', on the African continent or anywhere else, and deserves our strong support.

Allow me to also recognize the instrumental role played by the African Union Commission (AUC) in championing the inclusion of children, youth and the adult population living with disabilities in the workplace and in civic spaces.

In September 2020, the Commission adopted the 'AU Disability Inclusion Guideline for Youth Exchange' as a working document to aiming at providing equal access to opportunities for all African youth.

Equally commendable was the entry into force in June of the 2018 African Protocol on the Rights of Persons with Disabilities. This is an important milestone worth celebrating.

According to the World Health Organization (WHO) more than 80 million Africans – or 1 in 15 people on the continent – experience some form of disability.

The forms of disability vary widely, from physical disabilities to mental, intellectual, emotional and sensory disabilities and all kind of combinations, often with unknown cause.

It is not only the people living with disabilities that face challenges, but also their parents, brothers and sisters, friends, and others. This is where we need to reflect on what we can do to serve affected persons and their families, to assist them in achieving their full potential.

#### Ladies and gentlemen,

In the name of our common humanity, we have a special responsibility towards one another, notably by increasing our knowledge and understanding of people living with disabilities, including Down syndrome.

We know for sure that the quality of life of people with Down syndrome can be significantly improved, by proactively providing them with adequate medical care, ensuring regular check-ups to monitor mental and physical condition. We must support them with timely interventions, be it physiotherapy, occupational therapy, speech therapy, counselling or special education.

#### Ladies and gentlemen,

People with Down syndrome and other disabilities often remind us that: Stereotypes stop them from being treated fairly, like other people.

They often fill belittled, underestimated and excluded from many aspects of our social life. And even more troubling, they are often treated very badly if not abused.

In many societies there simply is a lack of proper knowledge of Down syndrome, and the required understanding on how to ensure inclusion of concerned of children and young adults in the wider society. Even the few organizations that are active in this field suffer from the same knowledge gaps.

This in turn limit the ability of people with Down syndrome to unleash their fullest potential and actively take part in their communities' life experience.

In more informed societies where there is a combination of increased knowledge, awareness raising and improved medical and other services, the lives of people with Down syndrome have dramatically improved.

In this regard, the commitment of all three divisions of the AU Department of Health, Humanitarian Aid and Social Development to addressing the issues and challenges I have just alluded to is encouraging.

As we pursue our collective efforts to live up to the AU's theme of the year 2024, "Education and lifelong learning", let's all recommit to better educate ourselves on the challenges facing people with Down syndrome.

This will also improve our understanding of their strengths and skills so that we may enable them to run more independent, richer, and fulfilling lives within their families and communities.

The United Nations looks forward to diligently work with the African Union in this critical field, alongside other strategic partners with a view to providing better care for children with Down syndrome and other intellectual disabilities.

## THANK YOU for joining us as carry on this noble journey.