

Concept Note for Proposed Side Event

CSW 67, United Nations Headquarters, New York

Proposed Title: Autism and Down syndrome know no borders: Mothers, Families and Professionals laying the foundation for protection and fulfillment

To commemorate the 18th anniversary of World Down Syndrome Day - WDSO 2023

Date and Time:

Friday, March 17

1:15 - 2:30 PM

Venue: UN Conference room 2

Sponsor Member State: Permanent Mission of Cameroon to the United Nation

Description:

This side event will bring together Down syndrome and autism advocates and experts to discuss the challenges women and families face raising children with development disabilities. It will address concrete cultural, legal, and policy changes that can help women and families welcome and care for children with Down syndrome and autism including with their transition from youth into adulthood.

Background:

In every country, there are children with Down syndrome or autism. Children affected by these distinct conditions may face lifelong physical and cognitive challenges of varying severity, but they remain valued and beloved family members and contribute to their communities in a wide variety of ways. Regardless of the level of their disability, people with these diagnoses have equal rights and dignity and are entitled to support and protection at every level. However, helping them achieve their full potential and receive the care they require involves unique challenges for them and their families, beginning before birth and extending throughout their lifetimes.

Global consensus holds that every person has a right to life, and that the family is the natural and fundamental group unit of society, entitled to support from society and the state. For the United Nations and its member states, which affirm that global policies must leave no one behind, the way persons with disabilities and their families are supported is a crucial indicator of their commitment to that ideal. This begins with a commitment to eradicate the eugenic practices that have led to the deaths and ostracization of persons with conditions like Down syndrome, from selective abortion to inhumane institutionalization practices.

Social science findings have shown that the parents and families of persons with development disabilities love and cherish them, but face unique challenges in providing the needed resources, including special educational programming, routine caregiving, and medical treatments. These challenges are exacerbated by poverty, social instability, and other factors.

This event will explore the practical ways that the international community, national governments, and professional organizations can create enabling, family-centered environments where people with autism and Down syndrome, along with their parents, families, and communities, can fully thrive.

Co-Sponsoring Organization:

Center for Family and Human Rights (C-Fam)

Program

Welcome: Lisa Correnti, Executive Vice President, C-Fam

Opening Video: Happy World Down Syndrome Day

Opening Keynote: Marie Catherine Ondoua Abena, Minister of Women's Empowerment and the Family of the Republic of Cameroon (5 minutes)

Video Address:

The Honorable Steve Daines, Member of U.S. Senate, Sponsor of legislation to protect babies with Down syndrome, "The Protecting Individuals with Down Syndrome Act"

Confirmed Panelists: (

"Trisomy Triathlete," Eighteen-year old Gabriel Cobb who has Down syndrome shares his passion for life and competing in triathlons.

"My name is Everett and I am Autistic," Seven-year old Everett McKiernan and his mom Emily share how early development intervention and inclusive education have helped him thrive.

"Embrace – Don't Erase Down Syndrome," Kurt Kondrich and his nineteen-year old daughter Chloe, discuss how he became a Dad-vocate and their work in passing legislation in Pennsylvania (Chloe's Law) to assist parents that receive a pre-natal diagnosis of Down syndrome. It is now being replicated across the United States.

Video: Imprint Hope

Promoting the dignity and value of people with disabilities in Uganda, Clare Byrne, Founder and Director, Imprint Hope

Positive strides and challenges in making Sierra Leone a disable - friendly country, Ms Sia Fasuluku, Dir. Research, Planning and Development, Min. of Technical and Higher Education (MTHE), Government of Sierra Leone

The importance of research to improve the lives of those with Autism and Down syndrome, Michelle Sie Whitten, President, Global Down Syndrome Foundation

Video: Frank Stephens Congressional Testimony

Video Address: Frank Stephens Address the UN

Pending Panelists (by video):

“A testimony of living with Autism or Down Syndrome in Cameroon: As if the Damn of the Earth, left further behind, being cursed and helpless”, Mrs. Helene MINKOULOU, Parent and President of ASEVIMAR, Association for the Supervision of Child Victims of Rare Diseases

“Looking ahead: Support, education, and socio-professional integration of people with autism and Down Syndrome in a developing country: challenges and prospects”, Zaboya Dama Adele Judith Epse Makomra, Msc Biology, Environment and Sanitation, Promoter in the implementation of a day-care and socio-professional training center for Autistic and people with Down Syndrome in Yaoundé

Combating prejudices and stereotypes against Down Syndrome and Autism: together, let's raise awareness to ensure the social inclusion of autistic and People with trisomy, Yves Akamba, Vice President of the Center for Applied Research on Sustainable Development, and artist musician advocacy for social inclusion, and Pascaline Ngoni Etoundi, Member of GIC Oyili in favor of socioprofessional integration of people with disabilities in the agriculture sector.

Comments, questions, answers if applicable

Closing Remarks by Permanent Representative of the Mission of Cameroon to the UN