

“Celebrating ability: investing in and accompanying children and adults with Down syndrome and their families”

21 March 2024

Permanent Observer Mission of the Holy See to the United Nations, 21 March 2024

On 21 March 2024, the Permanent Observer of the Holy See to the United Nations held a side event together with the Center for Family and Human Rights entitled “Celebrating Ability: Investing in and Accompanying Children and Adults with Down Syndrome and their Families,” at UN Headquarters in New York during the Commission on the Status of Women.

In his opening remarks, H.E. Archbishop Gabriele Caccia identified common themes of inclusion, education, and opportunity between the Commission on the Status of Women (CSW) and the Down Syndrome Day. He stressed that everyone has limitations and needs support as part of the human experience shared by all. Archbishop Caccia criticized the focus on limitations rather than the capabilities of individuals with Down syndrome, which has led to a disturbing trend towards the termination of pregnancies following prenatal diagnoses. Recognizing our common humanity and the importance of support for everyone to thrive, he underscored that it helps dismantle misconceptions and fosters an inclusive community where all individuals can contribute meaningfully. Archbishop Caccia highlighted the UN’s commitment to human rights for all, emphasizing the need for comprehensive support systems for people with Down syndrome and their families, including education, healthcare, and employment opportunities. He concluded by emphasizing the intrinsic value of individuals with DS, asserting they are a gift to their families and society.

Mother and daughter Down syndrome advocates Patricia Hass and Isabella Hass, who has Down syndrome, spoke next. Patricia Hass described motherhood to Isabella as her “greatest joy and blessing,” emphasizing that her daughter inspires and teaches her daily. Ms. Hass described her experience raising Isabella, especially criticizing the negative framing by doctors at the time of her birth. She emphasized the need for a shift in healthcare perspectives, emphasizing that individuals with DS can pursue various professions, form meaningful relations, and deserve equal dignity. She argued that inclusive environments benefit everyone, noting that children with DS thrive academically and socially when exposed to education that challenges them. Addressing the challenges of raising children, she affirmed, “We love our kids. We are happy with our kids,” and opposed abortion on the basis of prenatal Down syndrome diagnosis.

Isabella Hass spoke about her work as a public speaker, athlete, and student. Like many other young women, she enjoys traveling and going to the beach and considers herself a foodie. She spoke about the positive impact of being fully included in school. She learns from her peers, emphasizing “we all have things to learn and things to teach.” She underscored that, “we are more alike than different... we don’t want your pity. We want to show you what we can do.” Her life goal is to advocate for children with Down syndrome and promote their inclusion. She shared a message to all persons with DS: “You are not alone.”

Dr. Brian Skotko shared the outcomes of his research on pregnancy outcomes. He spoke about the “reduction rate”, a measure that indicates the percentage of babies with a prenatal diagnosis of DS that were terminated due to the diagnosis. The reduction rate in the United States is 36% (babies who would have been born with DS were terminated). He also noted that people with DS in the United States are living longer, with an average lifespan of about 60 years of age. While the reduction rate has been increasing globally, the world is also seeing increases in the number of people with Down syndrome, primarily due to improved healthcare. He also introduced a research article on quality of life, mapping the levels of community inclusion, education, healthcare, independence, and policies for people with Down syndrome. He also spoke about a program, the Down Syndrome Societal and Social Services Survey, and his project, Down Syndrome Clinic to You (DSC2U), which offers care for people with Down syndrome and resources for medical practitioners.

Mr. Mark Bradford spoke about the story of Ven. Jérôme Lejeune and his discovery of the genetic cause of Down syndrome. He mentioned the UN Declaration on the Rights of Disabled Persons and the 1990 Americans with Disabilities Act, emphasizing the protection of individuals with disabilities. Bradford also pointed out antecedents to modern disability discrimination in the historical eugenics movement which aimed to eliminate those deemed inferior. Advances in ultrasound and prenatal screening technologies have exacerbated this issue, particularly as many abortion laws carve out exceptions to gestational limits when there is a disability diagnosis in utero. He criticized the societal push towards eliminating individuals with “chromosomal

abnormalities," explicitly condemning the idea that some countries eliminate Down syndrome, as this relies not on preventing Down syndrome from occurring but on ending the lives of those who receive a diagnosis before birth. Bradford argued that Down syndrome is compatible with a fulfilling life and urged society to recognize and value the lives and gifts of its members with Down syndrome.

Mr. Frank Stephens emphasized, "If you remember only one thing from today, it's that I am a man with DS, and my life is worth living." He outlined how advancements since the mid-20th century have vastly improved lives for those with DS, yet challenges persist, exacerbated by the combination of prenatal testing and discriminatory attitudes. Stephens described the historical institutionalization and social isolation of people with Down syndrome, contrasting these practices with his fulfilling life filled with accomplishments, including advocacy and acting roles. He countered the myth that DS lives are fraught with suffering, instead highlighting the richness and potential for a full life. He uses his speech earnings to support medical initiatives in Tanzania, illustrating his commitment to making a difference. Concluding optimistically, Stephens pointed to the strides made in societal inclusion and acceptance for individuals with DS while noting the ongoing need to update public information on Down syndrome and address Alzheimer's disease, which people with Down syndrome are at higher risk of, as critical challenges ahead.