Concept Note for the Side Event Entitled

“No Room in Rural Villages, Cities and Homes for Those with Disabilities? Are Girls and Boys with Down Syndrome Being Left Behind?”

To be held during the 62nd Session of the Commission on the Status of Women
And in anticipation of the 13th Commemoration of World Down Syndrome Day (3-21)

UN HQ Conference Room 12
March 20, 2018 • 1:15-2:30 pm

Background

One of the overarching commitments of the 2030 Sustainable Development Agenda is the pledge, found in the Preamble of Transforming Our World: The 2030 Agenda for Sustainable Development, that “no one will be left behind” (A/Res/70/1).

One of the least commented upon forms of discrimination against women and girls happens before birth. In 2008, Mara Hvistendahl published “Unnatural Selection,” a monumental work that documents global sex-selection and the consequences that will likely come to the world from what she calls the international deficit of 160 million girls who have gone “missing,” because they have been preferentially chosen to have their lives terminated through abortion.

As alarming as the discrimination of females in the womb is, in both developing and developed countries, however, there is another far more widespread discrimination happening on the basis of genetic screening: that of those with disabilities, particularly Down Syndrome. In recent months there have been reports that two countries have virtually “eradicated” Down Syndrome, not by finding a cure for Trisomy-21, but rather by eliminating those with Down Syndrome before they’re born. Statistics in those countries show that one hundred percent of expectant parents who receive a genetic screening positive for Down Syndrome for their child growing in the womb opt to terminate the child’s life before birth. In most other countries for which statistics are available, the rate of termination after a positive genetic test (whether accurate or a false positive) is over 90 percent.

The Convention on the Rights of Persons with Disabilities (CRPD), adopted on December 13, 2006 (A/Res/61/106), stresses in its first Article that its purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.” It specifies, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (emphasis added). The entire Convention begins with State
Parties recognizing that “the United Nations, in the Universal Declaration of Human Rights and in the International Covenants on Human Rights, has proclaimed and agreed that everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind,” and the Universal Declaration of Human Rights states candidly, in Article 3, that “everyone has the right to life, liberty and security of person.”

Is the right to life, liberty, security, promotion of respect for their inherent human dignity, protection and the full and equal enjoyment of all human rights and fundamental freedoms of those with Down Syndrome being ensured? While there have been many advances in countering discrimination against persons with disabilities in general, what is being done to ensure that those diagnosed with Down Syndrome aren’t being left behind in rural settings, in cities, or anywhere their lives are threatened?

The November remarks of one of the members of the UN Human Rights Committee, Mr Yadh Ben Achour of Tunisia, are an alarming illustration of a lack of respect for the dignity and rights of those with disabilities in general and Down Syndrome in particular. He stated during an official meeting of the UNHRC, “If you tell a woman, ‘Your child has … Down Syndrome … or that he may have a handicap forever, for the rest of his life,’ you should make this woman, it should be possible for her to resort to abortion to avoid the handicap as a preventive measure.” Defending those with Disabilities, he said, “does not mean that we have to accept to let a disabled fetus live.” Is this consistent with the UN’s concern to leave no one behind and to defend the rights of those with disabilities?

On December 19, 2011, the General Assembly declared March 21 as World Down Syndrome Day (A/RES/66/149) to be observed annually beginning in 2012 and invited all Member States, relevant organizations of the United Nations system and other international organizations, as well as civil society to observe World Down Syndrome Day to raise public awareness throughout society, including at the family level, regarding persons with Down syndrome. March 21 (3-21, for Trisomy 21) has been the annual observance of World Down Syndrome Day by advocacy and research groups for those with Down Syndrome since 2006.

On the first observance of World Down Syndrome Day at the United Nations on March 21, 2012, then Secretary General Ban Ki Moon said, “On this day, let us reaffirm that persons with Down syndrome are entitled to the full and effective enjoyment of all human rights and fundamental freedoms. Let us each do our part to enable children and persons with Down Syndrome to participate fully in the development and life of their societies on an equal basis with others. Let us build an inclusive society for all.”

In anticipation, therefore, of World Down Syndrome Day, and to see to build that society inclusive of all that enables children with Down Syndrome to participate fully in the development and life equally with others, several persons with Down Syndrome, their mothers and fathers, as well as advocates for those with disabilities are sponsoring a side-event. Panelists will focus on the unique and inherent dignity of people with intellectual and development disabilities, particularly those with Down Syndrome. It will examine successful policies and programs that have helped individuals with

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Down Syndrome and their families thrive to lead fulfilling lives. Panelists will also address current challenges of safeguarding the rights of persons with intellectual disabilities.

Speakers

- **Archbishop Bernardito Auza**, Permanent Observer of the Holy See to the United Nations
- **Mary O'Callaghan, Ph.D.**, Developmental Psychologist from the Center for Ethics and Culture at the University of Notre Dame, mother of a boy with Down Syndrome and other disabilities.
- **Patricia White Flatley, MD**, Research Down Syndrome Foundation and former Board Chair of Down Syndrome Research and Treatment Foundation, Emeritus Board Member of Lumind Foundation, and mother of a boy with Down Syndrome.
- **Mrs. Deidre Pujols** and daughter **Miss Bella Pujols**, Pujols Family Foundation, dedicated to the love, care and development of people with Down Syndrome and their families.
- **Mr. Kurt Kondrich** and daughter **Miss Chloe Kondrich**, who was the inspiration for the Down Syndrome Prenatal Education Act (“Chloe’s Law”) that was enacted in Pennsylvania to provide pregnant women with information about Down Syndrome and how individuals with Down syndrome and their families can thrive and lead fulfilling lives. It is now being replicated across the United States.
- **Miss Mikalya Holmgren**, the first woman with Down Syndrome to compete in the Miss Minnesota USA Pageant and the winner of the Spirit of Miss USA Award.
- **Randall Wright**, Director of the movie *Summer in the Forest*, to be released in New York City March 23.

Sponsors


Registration

To RSVP for the event, please visit holyseemission.org/rsvp20March2018 by March 13. All those without UN grounds passes (for example, UN Delegates passes, NGO passes, or CSW passes) must register for a special event pass at this link. Those with UN passes are asked to register as well to ensure that there is enough space for them in the room. If the event fills to capacity, only those who are registered will be admitted.