Social protections For Women, Girls And All Those With Down Syndrome

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Statement by H.E. Archbishop Bernardito Auza, Apostolic Nuncio, Permanent Observer of the Holy See
At the Side Event entitled *"Social Protections for Women, Girls and All Those with Down Syndrome"* United Nations, New York, 21 March 2019

Your Excellencies, Distinguished Panelists, Dear Friends,

I am very happy to welcome you to this morning's event on social protections for women, girls and all those with Down Syndrome, which the Holy See is pleased to be sponsoring, on this International Down Syndrome Awareness Day, with the Center for Family and Human Rights.

During the 63rd Session of the Commission on the Status of Women that has been taking place over the last ten days, we have been focused on the theme of social protections, access to public services and sustainable infrastructure to achieve gender equality and the empowerment of women and girls. We have considered the gaps in these protections and the various vulnerabilities to which women and girls are exposed. We have examined the situation of access in places across the globe to services like education, work, health care, and infrastructure like housing, energy, water and sanitation, and have looked at the discrimination that is often at the root of why people are deprived of them.

But what is a situation of concern for all women across the globe is particularly acute for women and girls with Down Syndrome, as well as parents of Down Syndrome children. And if there is one area in which there does not seem to be much of a variance between girls and boys it is with regard to what happens when parents receive a diagnosis of Down Syndrome. In many countries that diagnosis is sadly tantamount to a death sentence. Despite the assurances of the 2006 Convention on the Rights of Persons with Disabilities to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities," including "those who have long-term physical, mental, intellectual or sensory impairments," and to "promote respect for their inherent dignity," there are really no social protections for those diagnosed in the womb with a third 21st chromosome. For children born with Down Syndrome, in many places access to public services — to education, work, adequate health care — is inadequate or non existent. And in places with lagging infrastructure, the difficulties for those with Down Syndrome and their families can be exacerbated. Their special needs are often largely overlooked, including by an international community that is committed to leaving no one behind and ensuring the full and equal enjoyment of all human rights of persons with disabilities.

Back in 2011, the UN General Assembly made a commitment to ensure that those with Down Syndrome would not be left behind. With Resolution 66/149, it declared March 21 as World Down Syndrome Day and invited all Member States, relevant organizations of the United Nations system, other international organizations, and civil society to observe it annually in order to raise public awareness throughout society, including at the family level, regarding persons with Down Syndrome. March 21 (or in numerals 3-21 for Trisomy-21) had previously been marked from 2006 as World Down Syndrome Day by advocacy and research groups.

On the first observance of World Down Syndrome Day at the United Nations seven years ago today, then Secretary-General Ban Ki-Moon said, "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."

But it's a struggle to build that inclusive society. In 2017, a major US television network reported that one country was on the verge of eliminating Down Syndrome, but what it really meant was that it was eliminating those with Down Syndrome, because practically 100 percent of parents of babies who receive a prenatal diagnosis of Down Syndrome were choosing to end the life of their son or daughter. Several other countries have similar statistics, to such a degree that many defenders of the rights of those with Down Syndrome, and other objective observers, call what is happening to children diagnosed with Trisomy 21 in the womb a "genocide."

Even some within the UN System, despite the Convention on the Rights of Persons with Disabilities, despite the stated commitment of the UN General Assembly, are abetting that genocide. In November 2017, one of the members of the United Nations Human Rights Committee, based in Geneva, stated during an official meeting, "If you tell a woman, 'Your child has … Down Syndrome … or that he may have a handicap forever, for the rest

of his life,' … 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." Such a position is baldly inconsistent with the UN's concern to leave no one behind and to defend the rights of those with disabilities. As Dr. Jerome Lejeune, who discovered the cause of Down Syndrome in 1958, once said, after what he had discovered was being against rather than in favor of those with Down Syndrome, "Medicine becomes mad science when it attacks the patient instead of fighting the disease." He underlined, rather, that "we must always be on the patient's side," and that the practice of medicine must always be to "hate the disease [and] love the patient."

Pope Francis said in 2017 that the response to the eugenic trend of ending the lives of the unborn who show some form of imperfection is, in short, love. "The answer," he said, "is love: not that false, saccharine and sanctimonious love, but that which is true, concrete and respectful. To the extent that one is accepted and loved, included in the community and supported in looking to the future with confidence, the true path of life evolves and one experiences enduring happiness."

And the happiness of those with Down Syndrome, and the happiness they bring to others, cannot be denied. A 2011 Study published in the American Journal of Medical Genetics by Harvard University Researchers associated with Boston Children's Hospital showed that 99 percent of those with Down Syndrome say they are happy with their lives, 97 percent like who they are, 96 percent like how they look, 99 percent of them love their families, 97 percent like their siblings and 86 percent said they make friends easily. It also showed that 99 percent of their parents said they love their child with Down Syndrome, and 79 percent said that their outlook on life is more positive because of their child. And among siblings 12 and older, the survey indicated that 94 percent said they are proud to have a brother or sister with Down Syndrome, and 88 percent said they are better people because of him or her.

I cannot think of any other situation that would show such high numbers among children with a particular condition or no condition at all, and among their parents, and siblings. We could even say that Down Children and their families are simply among the happiest groups of people alive — and the world is happier because of them.

We'll have a chance today to hear from our panel — Karen Gaffney, Michelle Sie Whitten, Deanna Smith and Rick Smith — where this infectious happiness comes from.

I thank you for your attendance today and for your interest in providing social protections and access to public services — indeed full and effective enjoyment of all human rights and fundamental freedoms — for all those with Down Syndrome, and for working not only to build a society that includes them, but cherishes them, and benefits from their presence and many gifts.