

Remarks by Ms. Leslie Wade
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DESA

Second High-Level Event of the NGO Committee for Rare Diseases

Thursday, 21 February 2019, 9:45 – 10:45 a.m.

Conference Room 8

Excellencies,
Ladies and Gentlemen,

I am pleased to join you on the occasion of Rare Diseases Day. On behalf of Marion Barthelemy, Director of the Office of Intergovernmental Support and Coordination for Sustainable Development, I would like to thank the NGO Committee for Rare Diseases for the invitation to participate. It is an important moment to reflect on this issue, which receives very little attention in our debates here at the United Nations.

We have come a long way since the Millennium Development Goals. The MDGs, with three health-specific targets, were successful in galvanizing action on health and well-being. But we need to go further. The 2030 Agenda and the Sustainable Development Goals provide a template for that. The adoption of the SDGs remains a high point in the history of the United Nations. It is still a marvel that all countries could come together and unanimously adopt such an ambitious and detailed agenda.

The Agenda and the Goals remain a source of great optimism for countries and people. The vision set out in the Declaration is for “a world free of fear and violence, of universal literacy, of equitable and universal access to quality education, health care and social protection, where physical, mental and social well-being are assured.” It is anchored in the premise of leaving no one behind. This is why the Agenda is a beacon of hope for people with rare diseases and those who accompany them.

I commend the NGO Committee on Rare Diseases for taking the full measure of what the SDGs can mean for people with rare diseases. You have outlined the debilitating burden for people with diseases that are not recognized and for which little treatment exists. You have analyzed thoroughly how addressing their plight will contribute to realizing the SDGs, and how the SDGs bring new momentum to supporting people with these diseases.

I would like to recall the in-depth review of SDG 3 in the 2017 HLPF which provides a basis to build on. In its Ministerial Declaration, the Forum acknowledged that “investment in health contributes to reducing inequality, to sustainable and inclusive economic growth, social development, environmental protection, and to the eradication of poverty, hunger and malnutrition.”

The lack of adequate investment in research and innovation, access to diagnostics, medicines and treatments for the 6000 conditions that are considered rare **is a clear threat to the principle of leaving no one behind**. All stakeholders present here today would need to step up efforts to ensure that the affected population – though relatively small, will benefit from sustained attention and investment.

2019 presents another opportunity to advance the cause. The theme of the 2019 high-level political forum (HLPF) in July on “Empowering people and ensuring inclusiveness and equality” is particularly relevant for this important constituency. Your contribution and participation should be active and visible.

The SDGs under review this year will include SDG 4 on quality education; SDG 8 on decent work and economic growth; SDG 10 on reducing inequalities; SDG 17 on means of implementation and partnerships; alongside SDG 13, and SDG 16. SDGs 4, 8, 10 and 17 are where your contribution could be the most impactful.

On SDG 4, you have told us that 50 per cent of rare diseases affect children. It affects their ability to attend and complete school and to have satisfying economic and social opportunities to improve their lives and livelihoods. This also relates to SDG 8. Here you have also told us that persons with rare diseases and disabilities are often unable to work because they do not have proper access to accessible facilities, flexible working hours and roles suitable to their situations. On SDG 10, we know that people with rare diseases tend to be marginalized and are often invisible and excluded from participating in public life. They often do not have a say in identifying their needs and how best they would like them to be met. Many of the disadvantages are also compounded by gender bias. And SDG 17 also gives us hope – because more and better partnerships can amplify your advocacy and generate results – more investment, more research and effective and accessible treatments.

As you know, the HLPF will meet twice this year. It will also meet under the auspices of the General Assembly in September at summit level. The SDG Summit will be reviewing overall progress on the 2030 Agenda and all 17 SDGs. It will identify progress and persisting and emerging challenges, provide political guidance on implementation, and mobilize further action to accelerate implementation. As you also know, a high-level meeting on universal health coverage will also be convened by the President of the General Assembly on the third day of the opening of the seventy-fourth session.

This is an important moment that must be seized. It is an opportunity for civil society, including the Committee on Rare Diseases, to continue efforts to mobilize action and hold Governments and all partners accountable for ensuring access of all to health services.

Your contributions to the implementation of the 2030 Agenda and the achievements of the SDGs will be critical to ensure that no one is left behind – including our friends, families, neighbours, co-workers and others with rare diseases.

Thank you.